

WHO-FIC NETWORK MEETING

Tokyo, Japan
16-22 October 2005

The ICF-CY: a derived classification for children and youth

Rune J. Simeonsson, Matilde Leonardi, Eva Bjorck-Akesson, Judith Hollenweger, Don Lollar,
Andrea Martinuzzi, Huib Ten Napel

ICF-CY The ICF for children and youth is a derived classification to extend coverage of the main ICF volume for documentation of body functioning, structures, disability and health of children in the first two decades of life. A total of 237 changes were made to the ICF-CY of which 99 were expansions of inclusion and exclusion criteria and 28, 100 and 10 new codes were additions at the 4-, 5- and 6-character level respectively. As a derived classification, the ICF-CY is designed to provide a common language of documentation that can be used across disciplines, sectors and countries to advance services, policy and research on behalf of children and youth.

Overview The International Classification of Functioning, Disability and Health for Children and Youth (ICF-CY) has been prepared as a derived version of the ICF (WHO, 2001). The second draft of the ICF-CY provides content to document the characteristics of children and youth of importance for promoting their health, growth and development. It is intended for use by clinicians, educators, policy makers and researchers involved in services, policy and research with children and youth. As a derived version of the ICF it is designed to provide a common and universal language for clinical and research documentation of health and disability in child populations.

Rationale The development of the version for children and youth was carried out in response to the request by WHO for a version of the ICF for universal use with children in health and health related sectors. The need for a version for children and youth was based on recognition that the first two decades of life consist of rapid growth and significant changes in physical, social and psychological development. Further, the manifestations of disability and chronic conditions in childhood and adolescence are different in nature, intensity and impact than those of adults. To account for these differences, classification content for the ICF-CY was selected that was sensitive to changes associated with developmental characteristics of different age groups. The development of the derived version of the ICF for children and youth drew on multiple sources of evidence. These sources included content from (1) international conventions for children and youth; (2) scientific expertise of the working group and consultants; (3) theoretical and conceptual contributions; (4) research findings; (5) field trial results; (6) findings from related ICF/ICF-CY implementation studies and (7) publications of the work group.

Development activities The development activities of the WHO work group have been carried out over the period 2002 to 2005 and supported by the National Center on Birth Defects and Developmental Disabilities of the Centers for Disease Control, USA. Drawing on the guidelines in Annex 8 of the ICF, the version for children and youth was designed to be completely consistent with the organization and structure of the main volume. Derivation of the content for the ICF-CY consisted of the following major modifications. New codes were added to unused numbers to describe functions either unique to children or particularly relevant to children (e.g. playing; mouthing). Selected codes were suppressed for described functions that were not pertinent or relevant to children and youth (e.g. menopause). Definitions were expanded to make them more readily applicable to children and more easily understood by people dealing with children. This took the form of changes of addition of examples pertinent to children and adolescents. In some cases the wording "as appropriate for age" was added to clarify applications of content for children. Modifications of inclusion-exclusion criteria were made to facilitate use by parents, health care workers, teachers and others involved directly or indirectly in services for children.

Analysis of the derived classification using the Classification Workbench (ClAML-XML) revealed that a total of 237 additions had been made to the ICF-CY. Of these, 99 were expansions of inclusion and exclusion criteria and 28, 100 and 10 new codes at were added at the 4-, 5- and 6-character level respectively.

The first draft of the ICF-CY was delivered to WHO officials at the WHO-FIC meeting in Cologne in the fall of 2003. This draft version of the ICF-CY was placed on the WHO website in the summer of 2004 for field trials. Responses to surveys and clinical questionnaires were provided by individuals and programs in various countries around the world. Field trial findings and evaluation by the work group served as the basis for preparing the second draft of the ICF-CY which was submitted to WHO in June, 2005. This second draft is being placed on the WHO website and will remain there for six months to secure comments and suggestions from around the world. The goal is for the ICF-CY to be approved for publication by WHO and available for distribution in 2006.

Summary Responses to dissemination activities by the work group and field trial findings provide evidence of substantial national and international interest in the ICF-CY as a classification for use in health and health related service settings for children. Professionals working with children and youth with disabilities endorsed the value of the ICF-CY with particular reference to the components of Activity, Participation and Environment. A range of applications have been recognized for the ICF-CY, including clinical documentation, policy formulation, surveillance and survey uses and research. The need for training to apply the ICF-CY in every day settings is an important priority.

The ICF-CY extends the coverage of the main ICF volume through the provision of specific content and greater detail to cover the body functions and structures,

activities, participation and environments unique to infants, toddlers, children and adolescents. With its functional emphasis, the ICF-CY makes available a common language of documentation that can be used across disciplines, sectors and countries to advance services, policy and research on behalf of children and youth.