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ICF-CY: a universal tool for practice policy and research

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Abstract

The development of the ICF for children and youth (ICF-CY) over the past five years has involved the expansion of content and increased specificity of detail to cover body functions and structures, activities, participation and environments to adequately capture the growth and development of infants, toddlers, children and adolescents. Field trial findings and research applications have provided support for the comprehensiveness of the ICF-CY for use in administrative, clinical and research settings with children of different ages and health conditions. Validation of the content of the ICF-CY has taken the form of clinical research studies to demonstrate its utility in assessment and classification of childhood disability.

There is wide spread national and international interest in the promise of the ICF-CY as a taxonomy for use in various health settings serving children with chronic conditions and disabilities. Of particular significance is the potential utility of the ICF-CY for sectors and systems involved in policy work and services for children and youth that have not had a common language or a standard classification. Social welfare, the legal system and public education are all engaged in services and supports for children and, for the first time will have a classification system with direct applicability to their spheres of work as well as offering a common language that can be shared across settings and disciplines. In this regard the ICF-CY can contribute to practice, policy and research in a number of ways. Specifically the ICF-CY can (a) provide a framework for inter-disciplinary practice; (b) yield profiles of child functioning; (c) clarify clinical diagnoses and co-morbidity; (d) provide a functional basis for planning individualized treatments/interventions; (e) offer codes for identifying intervention outcomes; (f) provide the basis for documenting the gradient and hierarchy of change of functioning; and (g) standardize documentation of variables in research. Implementation of the ICF-Cy is contingent on the availability of measurement tools that can provide documentation for the specificity and severity of ICF-CY codes. With the publication of the ICF-CY there is a need for instrument development to facilitate full implementation of the ICF for intervention, surveillance and research activities.

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Development of the ICF-CY

The publication of the International Classification of Impairments, Disabilities and Handicaps in 1980 by WHO represented a significant achievement in that it separated underlying health conditions from their consequences advanced a dimensional approach to disability and provided the first comprehensive taxonomy of disability. The adult orientation and restricted developmental content (e.g., learning) of the ICIDH made its applicability for children very limited (Diderichsen, et. al, 1990; Simeonsson et. al., 2000). The revision of the ICIDH with the publication of the International Classification of Functioning, Disability and Health in 2001 expanded the age range and coverage of functional limitations, however, its sensitivity to characteristics of functioning in children, particularly very young children was limited (Simeonsson et. al., 2003). The need for a version of the ICF encompassing characteristics of children and youth was based on the fact that the first two decades of life are characterized by rapid growth and development with significant changes in children's physical, social and psychological functioning. Further, the manifestations of functioning, disability and health conditions in childhood and adolescence are different in nature, intensity and impact from those of adults.

To account for these differences, characteristics associated with growth and development in children and youth were identified and added to the ICF in the development of a version for children and youth (ICF-CY). The ICF-CY expanded the coverage of the main volume through the addition of content and greater detail to encompass the body functions and structures, activities, participation and environments specific to infants, toddlers, children and adolescents. The ICF-CY covers the age range from birth through 17 years of age, paralleling the age range covered by other U.N. conventions (e.g., U.N. Convention on the Rights of the Child).

Applications of the ICF-CY

The ICF-CY offers a conceptual framework and a common language and terminology for recording problems involving functions and structures of the body, activity limitations and participation restrictions manifested in infancy, childhood and adolescence and environmental factors important for children and youth. The ICF-CY defines components of health and health-related components of well-being. Among children and youth these components include mental functions of attention, memory and perception as well as activities of play, learning, family life and education in different domains. As such, the descriptions and codes in the ICF-CY have greater granularity and may serve as precursors of more mature functioning as document in the ICF. With an emphasis on documenting functioning rather than establishing diagnoses, the ICF-CY offers utility across disciplines, government sectors as well as national boundaries to define and document the health, functioning and development of children and youth.

The information provided by the ICF-CY may be used in a variety of ways including clinical, administrative, surveillance, policy or research applications. In each case, ICF-CY codes can be used to document a single problem or a profile of limitations defining a child's difficulties of health and functioning. In this regard the ICF-CY can contribute to practice, policy and research in a number of ways. Specifically the ICF-CY can (a) provide a framework for inter-disciplinary practice; (b) yield profiles of child functioning; (c) clarify clinical diagnoses and co-morbidity; (d) provide a functional basis for planning individualized treatments/interventions; (e) offer codes for identifying intervention outcomes; (f) provide the basis for documenting the gradient and hierarchy of change of functioning; and (g) standardize documentation of variables in research.

Framework for inter-disciplinary practice

The value of the dimensional approach of the ICF-CY is that it changes the focus from classifying children on the basis of discipline specific diagnoses to a classification of functional characteristics of children. This is an important distinction and in keeping with a holistic and non-stigmatizing approach to disability. In this way the ICF can provide is a framework for integrating interdisciplinary efforts on behalf of children with disabilities. In this regard while the disciplinary activities of medicine, allied health, nursing, psychology and special education often correspond to different components of the ICF model, they can share the common language of the ICF in defining characteristics of the child and needed interventions and environmental supports. This addresses an important problem defining current practices in which discipline-specific languages may restrict a holistic and integrated view of the child.

Yield profiles of child functioning

An important way in which the ICF can contribute to clinical practice is in the derivation of profiles of child functioning. The purpose of the ICF is not to classify individuals but rather to classify impairments of body function or structure, activity limitations or participation restrictions that they may experience. This is an important distinction and in keeping with a holistic and non-stigmatizing approach to disability. In addition, documentation can also be made of environmental factors that represent barriers to functioning and performance of activities. The dimensional approach of the ICF emphasizes the fact that disability is not uni-dimensional but is manifested at different planes of experience of the child. Classifying different manifestations of disability across these dimensions generates a profile of intra-individual characteristics to define needs unique to the child. In these uses of the ICF-CY, parents, children and youth should be included when possible.

Clarify clinical diagnoses and co morbidity

The derivation of diagnoses in clinical for conditions such as autism, attention deficit hyperactivity disorder is typically based on evidence for the presence of a defined number of symptoms within a broader set of symptoms. The diagnosis of Autistic Disorder (DSM-IV TR; 299.0) specifies criteria of (1) a combination of impairments in the three domains of social function, communication, and atypical behavior; (2) delayed or abnormal functioning evident before the age of three and (3) the exclusion of other disorders. Although these criteria are used to establish the diagnosis of autism in clinical practice and research, the manner of combining evidence for impairment in the three domains contributes to variability in children with the diagnosis. Further, since the diagnosis can be made with some combination of 2 or more impairments of social function, 1 or more in communication and 1 or more in atypical/repetitive behavior. It is clear that the particular combination of impairments will be associated with children presenting with different expressions and severity of problems. To this end, the use of ICF-CY codes may be productively used to describe the functional characteristics of an individual child. As shown in the table, the use of ICF codes may also serve to differentiate two children sharing the diagnosis of autism but presenting with different functional limitations thereby clarifying the clinical diagnosis. A related application of the ICF-CY may be to address the problem of co morbidity in the assignment of diagnoses (Jensen et. al.,, 2006). In this regard, the use of ICF-CY codes may clarify both "successive" and "concurrent" co morbidity by displaying the functional limitations of the child manifested in both forms.

Use of ICF codes to clarify diagnosis of autism in two children

<ul style="list-style-type: none"> • Child A • b1142.3 orientation to person • b120.2 general cognitive functions • d310.3 communicating • d510.2 self care • d710.3 interpersonal interactions • Stereotyped movements • Severe mental retardation 	<ul style="list-style-type: none"> • Child B • b1142.3 orientation to person • b144.2 memory functions • d1600.2 attending to touch, face and voice • d130.3 copying • d310.3 communicating • d330.3 speaking • Moderate Mental Retardation •
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Planning individualized treatments/interventions

With the dimensional approach of the ICF-CY, the unit of classification is functional characteristics, not clinical diagnoses. The profiles of functional limitations derived from the ICF-CY are first and foremost descriptive of those factors that define a child’s difficulties in meeting the demands of daily living. The functional base of such profiles, particularly in reference to problems in performing activities should have direct and practical implications for the derivation of individualized intervention or treatment plans. To that end, documentation of the child-environment interaction may be productive in order to identify current barriers and needed facilitators that mediate learning and adaptation.

Framework for identifying intervention outcomes

An important use of the ICF-CY is as a framework for selecting measures consistent with domains or sub-domains of the ICF of relevance for assessment or outcome monitoring (Granlund et al., 2004). In this regard, the ICF-CY Participation codes define social and societal roles. The current focus on evidence-based practice would suggest that child outcomes of intervention or treatments reflect changes in participation. Thus the child’s mastery of skills, personal independence, social integration and developmental or academic transitions would constitute outcomes of special education consistent with ICF Participation codes.

Documenting the gradient and hierarchy of change of functioning

In tracking a child’s development or monitoring intervention effects, ICF-CY codes may be used to document change both in terms of the gradient and the hierarchy of change of body functions or structures, performance of activities or participation in social and societal roles. Gradient of change would be documented in circumstances in which there is a reduction of severity level within a code, for example a positive shift in “regulating behaviors within interaction” from d7202.4 (complete problem/impairment) to d7202.2 (moderate problem/impairment). Hierarchy of change would be documented in circumstances in which there is a movement from a lower level code to a higher level code, for example a shift in meeting task demands from undertaking simple task (d2100.2) to undertaking complex task (d2101.2).

Standardize documentation in surveillance and research.

In surveillance applications, a limited set of ICF-CY codes may be selected to standardize data collection procedures across instruments and over time in order to document prevalence of conditions, project service needs and service utilization patterns. In surveillance and research contexts, there is a need to have common data to aggregate in the documentation of the nature and distribution of functional limitations among children and youth (Hogan et al., 1997; McDougall & Miller, 2003; Wells & Hogan, 2003). Standardized documentation with ICF-CY codes could increase the precision of statistical databases with significant implications for documenting the type of resources used and for projecting future resource needs as a function of changing prevalence patterns. In research, selected ICF-CY codes may be used to standardize the characteristics of participants, the selection of assessment measures and the definition of outcomes.

Continuing issues

With the dissemination of the ICF there has been growing interest in its application in various fields including physical medicine, rehabilitation, psychology and nursing (Institute of Medicine, 2005; Heinen et al, 2005; Kearney & Pryor, 2004). In that the dimensional approach of the ICF-CY is consistent with emerging trends in practice, policy and research involving children and youth, a similar interest is likely (Simeonsson et al., 2003; Lollar & Simeonsson, 2005). The view of children's disabilities as variations of human functioning, rather than diagnosed disorders is consistent with parallel efforts of viewing children with chronic health conditions in a non-categorical framework (Stein & Silver, 1999; 2002). Recognition of the central role of the environment and its documentation is one of the significant contributions of the ICF-CY with important implications for children and youth with disabilities. Continued advances in assistive technology and engineering of the physical and social environment will result in expanded opportunities for achievement and participation. An important and challenging priority will be to identify the environmental factors that are effective in enhancing student functioning and performance in daily life settings. To that end, a common language for matching characteristics of the child with the environment can enhance the experience of students with disabilities and contribute to a fuller realization of their potential.

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