

ICF-CY: A Universal Tool for Documentation of Disability

Rune J. Simeonsson

University of North Carolina at Chapel Hill, NC, USA; and Jönköping University, Sweden

Abstract The *International Classification of Functioning, Disability and Health—ICF (ICF-CY)* conceptual framework offers a new paradigm and taxonomy of human functioning disability, which can be used to guide holistic and interdisciplinary approaches to assessment and intervention. In settings serving children, youth, or adults with disabilities, the *ICF-CY* can provide comprehensive documentation of its involvement in special education and rehabilitation. Implementation of the *ICF-CY* in early intervention, special education, and habilitation settings should build on the adoption of the dimensional framework for practice and corresponding applications in assessment and intervention practices. An important priority in such applications is the identification and development of instruments and assessment tools that can provide evidence for assigning severity levels to *ICF-CY* codes.

Keywords: *ICF-CY*, intellectual disabilities, taxonomies

INTRODUCTION

At the end of the 19th century, Down (1887) presented a medical paradigm of disability, in lectures titled “Some of the mental afflictions of childhood and youth” (p. 49). In that context, he proposed changes in terminology and a scientific classification to define disability. With reference to terminology, “idiot” and “imbecile” were deemed inappropriate and were to be replaced with “moron” and “feeble-minded.” These latter terms were intended to differentiate children whose condition had a congenital etiology from children whose condition had a postnatal onset with a gradual deterioration of function, respectively. In addition, he proposed a two-level classification, with the first level defined by criteria of ethnicity and the second by etiology, encompassing three subgroups: congenital, accidental, and developmental. Although Down’s classification of disability on the basis of ethnicity was not sustained, the etiological components he proposed remained central to subsequent medical models of disability.

At the end of the 20th century, a new paradigm of disability emerged in which the medical model was replaced with a model of disability recognizing the social and cultural contexts of disability. Fundamental elements of the “new paradigm of disability”

were (1) a holistic view of the person; (2) a focus on function over impairment; and (3) a conceptualization of disability as a disablement process defined by a person’s interaction with the environment over time (Verbrugge & Jette, 1994). An important implication of the disablement process perspective was recognition of the ongoing influence of the environment on functioning (Bronfenbrenner & Ceci, 1994), with the associated understanding that disability could be prevented or reduced with intervention begun earlier rather than later in a child’s development. Viewing disability as a developing process has been a primary assumption for providing intervention as early as possible in the developmental period in order to prevent or reduce disability.

Among challenges faced with the introduction of the new paradigm of disability in rehabilitation, special education, and early intervention, however, was the fact that existing classifications do not correspond to the holistic, functional perspective that the paradigm represents. Historically, the use of taxonomies such as the *International Classification of Diseases (ICD-10)*; World Health Organization (WHO), 1992) in rehabilitation has focused on medical conditions and etiology in which disabilities were attributed to the individual as an intrinsic characteristic of the person. The *Diagnostic and Statistical Manual of Mental Disorders—Text Revision (DSM-IV-TR)*; American Psychiatric Association, 2000), also used in rehabilitation and mental health contexts, has similarly diagnosed intellectual and developmental disabilities on the basis of symptoms of pathology. In special education and early intervention, disabilities have typically been defined in terms of categories of physical, mental, sensory, behavioral, or motor impairments that were often idiosyncratic to specific service systems. The variability of approaches to define disability has contributed to problems of service integration, policy, and informatics related to individuals with disabilities. In the context of services, the variability of terminology and

Received February 20, 2009; accepted March 18, 2009

Correspondence: Rune J. Simeonsson, PhD, M.S.P.H., University of North Carolina at Chapel Hill, 105G Peabody Hall, CB 3500, Chapel Hill, NC 27599-3500, USA. E-mail: rjsimeon@email.unc.edu

This article is an abridged version of an invited keynote address delivered at the 2nd IASSID Asia-Pacific Conference, Singapore, June 24, 2009.

Rune J. Simeonsson, PhD, MSPH, is professor of education as well as research professor of psychology, and fellow at the Frank Porter Graham Child Development Institute at the University of North Carolina at Chapel Hill, North Carolina. He is also a professor of special needs education at Jönköping University, Jönköping, Sweden.

classifications has hampered multidisciplinary approaches to assessment and treatment. With reference to policy, the taxonomic and categorical reliance on diagnosis not only has been problematic in terms of restrictive eligibility criteria for services but also complicated transitions across systems using different classification approaches. A third problem area associated with existing classification approaches such as *ICD-10*, *DSM-IV-TR*, and categorical assignment is the variability of terminology and impairment, pathology-based documentation. Parmenter (2004) has emphasized uniformity of terminology as essential to advance research, epidemiological studies, and the development of international statistical databases with reference to persons with intellectual and developmental disabilities.

Central to the problems identified above has been the lack of a conceptually based, comprehensive framework for defining disability and an associated taxonomy that encompasses dimensions of human functioning. History has shown that the definition and classification of disabilities have changed over time and will continue to evolve. With reference to intellectual and developmental disabilities, the 1997 and 2002 classifications published by the former American Association on Mental Retardation (Luckasson, et al., 2002) represented efforts to define characteristics associated with mental retardation and a system to define supports needed by individuals with the condition. While these classifications represented comprehensive approaches for planning supports, they were limited as conceptual models and as taxonomic standards (Simeonsson, Granlund, & Bjorck-Akesson, 2006). A comprehensive framework for classifying dimensions of human functioning is needed to set definitional standards for the field, to guide practice, and to advance policy and research for persons with intellectual and developmental disabilities.

The publication of the *International Classification of Functioning, Disability and Health—ICF* (WHO, 2001) reflected the paradigm change from a medical model to a biopsychosocial model. The ICF formalized the new paradigm of disablement, in which disability is viewed as the product of person–environment interaction and provides a multidimensional framework and taxonomy of four components of body functions and structures, activities/participation, and environmental factors. A version of the ICF for children and youth, *ICF-CY* (WHO, 2007), expanded the content of the four components by including documentation of child characteristics from infancy through adolescence. The availability of these classifications has contributed to significant interest in their promise as a common language for health and social services as well as education (Field & Jette, 2007). 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.

The *ICF-CY* offers for the first time a common language that can be used by professionals in allied health, rehabilitation, social work, and education to describe the functioning of children and adults with disabilities across settings and disciplines (Simeonsson, Simeonsson, & Hollenweger, 2008). The practice implications of the ICF for the field of psychology are evident in the development of a practice manual by the American Psychological Association (Reed et al., 2005). Of particular significance is the utility of

TABLE 1

Contributions of the ICF-CY for serving individuals with intellectual and developmental disabilities

A unifying framework for interdisciplinary work
A classification of dimensions functioning and health
Profiles of functional characteristics and limitations
Clarification of diagnoses and co-morbidity
Functional indicators for framing intervention and outcomes
Identification of environmental barriers and facilitators
Continuity of documentation in transitions across services and time
Common language for data management and health informatics
Standard reference for defining rights of children and adults with disabilities

the *ICF-CY* to document limitations of functioning in persons with disabilities and chronic health conditions in service settings that have lacked an alternative to classifications of static diagnoses such as the *ICD* and *DSM-IV-TR* (Simeonsson, Leonardi, Bjorck-Akesson, Hollenweger, & Lollar, 2003). The *ICF-CY*, for example, provides codes in the domain of body functions for classifying general mental functions as well as specific functions such as attention and memory. The activity domain covers aspects of learning, communication, meeting tasks demands, self-care, and other activities of daily living. The participation domain provides codes to document the extent to which persons with intellectual disabilities experience engagement or restrictions in life roles expected for age and gender. The environment domain allows coding facilitators or barriers to such involvement. Classifying the functional characteristics of intellectual and developmental disabilities across these dimensions can yield individual difference profiles from which needed supports or resources can be identified. This documentation of person–environment interaction can serve as the basis for intervention planning to promote an individual's skill performance and participation.

As a universal tool, the *ICF-CY* offers a range of clinical, policy, and statistical applications related to services and supports for persons with intellectual and developmental disabilities (Table 1). In settings serving children, youth, or adults with disabilities, the *ICF-CY* provides a comprehensive model and taxonomy for special education (Florian et al., 2006; Simeonsson et al., 2008) and child habilitation (Lollar & Simeonsson, 2005). The conceptual framework can guide a holistic and interdisciplinary approach to assessment and intervention based on the dimensional taxonomy of human functioning. In addition to implications for policy, research, and training, the *ICF-CY* is consistent with the growing focus on functional assessment. The practice of using administrative categories and diagnoses to determine eligibility for early intervention, special education, or rehabilitation is problematic in that categories and diagnoses often mask the individual's functional characteristics and lack the applicability for planning intervention. The *ICF-CY* offers an alternate approach yielding a profile of limitations of functioning, activities, and participation. Further, it emphasizes the identification of environmental factors that may influence such

functioning with implications for planning individualized interventions. In documenting environmental barriers with reference to functional limitations and participation restrictions, the *ICF-CY* can serve as a standard for rights of children and adults (Simeonsson, Bjorck-Akesson, & Bairrão, 2006), as defined by the *UN Conventions on the Rights of the Child* (United Nations (UN), 1989) and *Persons with Disabilities* (UN, 2006), respectively.

Given the central role of assessment in planning and evaluating intervention, the *ICF-CY* can advance evidence-based practice in a number of ways. Specifically, the *ICF-CY* can (1) provide the basis for differentiated assessment; (2) emphasize profiling of individual functioning; (3) clarify clinical diagnoses and comorbidity; (4) support the provision of services and supports on the basis of functional profiles rather than administrative categories or medical diagnoses; (5) enhance the correspondence between assessment and individualized intervention planning; (6) offer codes for identifying intervention outcomes; (7) provide evidence for progress by documenting the gradient and hierarchy of change of functioning; and (8) generate summary statistics of individuals or populations defined by functional characteristics.

The implementation of the *ICF-CY* in early intervention, special education, and habilitation settings should build on the adoption of the dimensional framework for practice and a corresponding approach to assessment and classification of functioning. As coding with the *ICF-CY* requires evidence based on assessment or measurement in order to define severity of limitations, there is a need for instruments and assessment tools that can be mapped to *ICF-CY* codes. A potentially useful implementation of the *ICF-CY* is the development of "core sets" of codes to summarize an individual's functional abilities. A core set consists of selected *ICF-CY* codes that serve as indicators of functioning for a specific condition. Core sets have been developed in rehabilitation medicine using *ICF* codes to characterize medical conditions (Cieza, et al., 2004) such as rheumatoid arthritis (Stucki & Cieza, 2004). The development of *ICF-CY* core sets related to intellectual and developmental disabilities could facilitate the application of the *ICF-CY* in multidisciplinary practices of assessment and intervention. In this context, however, a useful approach would be to develop core sets drawing on the domains of body functions and activities/participation to reflect aspects of an individual's functioning in response to the demands of everyday life.

Clinical applications and research studies with the *ICF-CY* are expanding rapidly with reference to applying the concepts of activities and participation, defining environmental factors, and framing service delivery models for children and adults with disabilities. As new policy and practice initiatives are being implemented around the world, evidence is emerging on the utility of the *ICF-CY* and ways in which it can contribute to enhanced participation and quality of life of children, youth, and adults with disabilities.

REFERENCES

- American Psychiatric Association. (2000). *Diagnostic and statistical manual of mental disorders—Fourth edition text revision*. Washington, DC: Author.
- Bronfenbrenner, U., & Ceci, S. J. (1994). Nature-nurture reconceptualized in developmental perspective: A bioecological model. *Psychological Review*, 101, 568–586.
- Cieza, A., Ewert, T., Üstün, T. B., Chatterji, S., Kostanjsek, N., & Stucki, G. (2004). Development of ICF core sets for patients with chronic conditions. *Journal of Rehabilitation Medicine*, (44 Suppl), s9–s11.
- Down, L. (1887). Abstracts of the Lettsomian lectures on some of the mental affections of childhood and youth. Lecture I. *British Medical Journal*, 8, 49–50.
- Field, M. J., & Jette, A. M. (2007). *The future of disability in America*. Washington, DC: National Academies Press.
- Florian, L., Hollenweger, J., Simeonsson, R. J., Wedell, K., Ridell, S., Terzi, L., et al. (2006). Cross-cultural perspectives on the classification of children with disabilities: Issues in the classification of children with disabilities: Part I. *Journal of Special Education*, 40, 36–45.
- Lollar, D. J., & Simeonsson, R. J. (2005). Diagnosis to function: Classification of children and youth. *Journal of Developmental and Behavioral Pediatrics*, 26, 323–330.
- Luckasson, R., Coulter, D. L., Polloway, E. A., Reiss, S., Shalock, R. L., Snell, M. E., Spitalnik, D. M., & Stark, J. A. (2002). *Mental retardation: Definition, classification, and systems of support*. Washington, DC: American Association on Mental Retardation.
- Parmenter, T. (2004). Contribution of the IASSID to the scientific study of intellectual disability: The past, present and the future. *Journal of Policy & Practice in Intellectual Disabilities*, 1, 71–78.
- Reed, G. M., Lux, J. B., Bufka, L. F., Trask, C., Peterson, D. B., Stark, S., et al. (2005). Operationalizing the International Classification of Functioning Disability and Health (ICF) in clinical settings. *Rehabilitation Psychology*, 50, 122–131.
- Simeonsson, R. J., Bjorck-Akesson, E., & Bairrão, J. (2006). Rights of children with disabilities. In G. Albrecht (Ed.), *Encyclopedia of disability* (pp. 257–259). Thousand Oaks, CA: Sage Publications.
- Simeonsson, R. J., Granlund, M., & Bjorck-Akesson, E. (2006). The concept and classification of mental retardation. In H. N. Switzky & S. Greenspan (Eds.), *What is mental retardation? Ideas for an evolving disability in the 21st century* (pp. 245–266). Washington, DC: American Association on Mental Retardation.
- Simeonsson, R. J., Leonardi, M., Bjorck-Akesson, E., Hollenweger, J., & Lollar, D. (2003). Applying the international classification of functioning disability and health to measure of childhood disability. *Disability & Rehabilitation*, 25, 602–610.
- Simeonsson, R. J., Simeonsson, N. E., & Hollenweger, J. (2008). International classification of functioning, disability and health: A common language for special education. In L. Florian & M. McLaughlin (Eds.), *Disability classification in education* (pp. 207–226). New York: Corwin Publishers.
- Stucki, G., & Cieza, A. (2004). The International Classification of Functioning, disability and health (ICF) core sets for rheumatoid arthritis: A way to specify functioning. *Annals of the Rheumatic Diseases*, 63 (Suppl 2), ii40–ii45.
- United Nations (UN). (1989). *UN convention on the rights of the child*. New York: Author.
- United Nations (UN). (2006). *UN convention on the rights of persons with disabilities*. New York: Author.
- Verbrugge, L. M., & Jette, A. M. (1994). The disablement process. *Social Science & Medicine*, 38, 1–14.
- World Health Organization (WHO). (1992). *International classification of diseases* (10th ed.). Geneva: Author.
- World Health Organization (WHO). (2001). *International classification of functioning, disability and health*. Geneva: Author.
- World Health Organization (WHO). (2007). *International classification of functioning, disability, and health—children and youth*. Geneva: Author.