

DERIVING DEVELOPMENTAL CODE SETS FROM THE INTERNATIONAL  
CLASSIFICATION OF FUNCTIONING, DISABILITY AND HEALTH, FOR CHILDREN  
AND YOUTH (ICF-CY)

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## **ABSTRACT**

Kirsten Marie Ellingsen: Deriving Developmental Code Sets from the International Classification of Functioning, Disability and Health, for Children and Youth (ICF-CY)  
(Under the direction of Rune J. Simeonsson, PhD)

Classifying childhood disability is a persistent challenge in health and education settings. Differences exist in the method and instruments used to identify and document childhood disability across settings, countries, and by professional discipline. This variability compromises reliable prevalence rates, limits valid comparisons of consequences of diagnosed conditions, and reduces knowledge about functional outcomes. Particularly challenging to establishing a standard classification system has been the lack of a universal definition and shared conceptualization of childhood disability.

These limitations were addressed with the International Classification of Functioning, Disability, and Health for Children and Youth (ICF-CY). The ICF-CY was endorsed by the WHO in 2007 and represents the first universal classification system available to document child health and disability. It also provides a common language and shared conceptualization of child disability across disciplines and countries and was designed to record the characteristics of developing children for multiple purposes, such as use in program planning, surveillance, research, and documentation of intervention outcomes (WHO, 2007).

Application of the ICF-CY is important to unify data on child health status, but the complexity and time required to use it limits its feasibility. This study was conducted to enhance the utility of the ICF-CY by asking international experts to identify essential categories of children's functioning during different developmental periods. The Delphi

technique was used as a formal consensus process to derive four code sets for children (a) birth to three years of age, (b) three through five years, (c) six through twelve years, and (d) twelve through seventeen years. A professionally diverse sample of 151 international experts representing all major world regions completed a series of iterative online surveys to rate the most important categories of child functioning to include in brief universal age-based “ICF-CY Developmental Code Sets”. The final code sets are intended to serve as a universal reference for minimal information to collect about child functioning in research, clinical practice, and policy for application in a global multidisciplinary context.

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## **CHAPTER 1**

### **Introduction and Review of Literature**

Classifying childhood disability is a persistent challenge in health and education settings. Differences exist in the method and instruments used for classification across settings and by professional discipline. Particularly challenging to the process of establishing a standard classification system is the lack of a universal definition of childhood disability (Florian et al., 2005; Simeonsson, 2006). A range of classification systems exists to identify disabilities, document consequences of diseases, and determine treatments; each system is embedded within a particular conceptual framework built on assumptions about human functioning and disability reflected by inclusion or exclusion of specific content (Florian et al., 2006).

In the absence of a standard classification system, there is considerable variability in the method and criteria used to diagnose or identify a disability. Moreover the theoretical model and underlying assumptions regarding concepts of disability and health in classification systems can influence the development and functioning of children. The practical application of theory becomes apparent when considering how conceptualization of childhood disability can facilitate access to support services by guiding where resources are directed, what information is collected and used to determine eligibility for services, and what areas are targeted for change in services.

On May 22, 2001 the World Health Organization (WHO) Member States endorsed the International Classification of Functioning, Disability, and Health (ICF) as a universal

framework for measuring health and disability ([www.who.int/classifications/icf](http://www.who.int/classifications/icf)). Guided by a biopsychosocial conceptualization, the ICF was designed to provide a common standard classification system of adult health and health-related domains including a comprehensive list of categories representing functioning at the body, person, and society levels. A derived version of the ICF for children and youth became available for worldwide use in 2007.

The International Classification of Functioning, Health, and Disability for Children and Youth (ICF-CY) is the first universal classification system of child health and disability. Before the ICF-CY, there was no standard universal classification system available to document child health and development through a common language and shared conceptualization across professional discipline and countries. It is also the first unifying framework that attempts to describe the effects of context and environment on child functioning. The ICF-CY is a comprehensive taxonomy of health and health related states; it is comprised of more than 1600 codes for children birth through seventeen years. The ICF-CY is a taxonomy designed to record the characteristics of developing children for multiple purposes, such as use in program planning, surveillance, research, and documentation of intervention outcomes in any setting and country (WHO, 2007).

The potential contribution of the ICF-CY in research, practice, and policy is vast, but the expansive content and relative complexity of the system have made efficient application difficult and time consuming. Efforts to promote the awareness and increase the utility of this system are therefore strongly warranted considering the valuable potential of the ICF-CY to address current problems in classifying child health and disability.

One strategy to increase the utility of the ICF-CY is to develop reduced item classification sets for a particular setting or purpose. To that end, this study was conducted to

develop reduced item sets to define the standard minimal content areas or ICF-CY categories essential for documenting child functioning within different ages groups that correspond to broad developmental stages (i.e., infancy and toddler-hood, early childhood, middle childhood, and adolescence) to derive universal “ICF-CY Developmental Code Sets”.

This paper begins with an introduction to the research topic and study. The Literature Review section provides an overview of relevant literature associated with child health and disability classification including a history of international classification systems and description of the International Classification of Functioning, Disability, and Health (ICF) and the International Classification of Functioning, Disability, and Health (ICF-CY). The section concludes with the rationale and goals for this study. The paper continues with a presentation of the Method, including a thorough overview of the Delphi technique used in the study, and data analysis plan. Findings from the three rounds of surveys are presented in the Results section. The items in the final ICF-CY Developmental Code Sets that were identified through the formal consensus process are presented at the end of the chapter. A summary of these findings and their implications are described in the Discussion section.

## **Review of Literature**

This literature review is divided into five major sections. The first section addresses the background and rationale for child classification systems. The second section presents an overview of the history of health and disability classification systems, and paradigms of disability. The third section describes challenges related to documenting child health. Next, the fourth section reviews limitations of classification systems. The fifth section then provides a review of the WHO International Classification of Functioning, Disability, and Health (ICF) and ICF-CY as the derived first universal classification of child health, disability and functioning. The review of literature concludes with a discussion about ICF and ICF-CY applications including development and field trials of reduced item sets.

According to a recent publication by the UN Children's Fund, the overall prevalence rates of child disability ranges from 0.4% to 12.7% with the estimates of prevalence rates varying by study, definition, and measure selected. In the US, more than one in ten school children have been evaluated and found to have a disability (The Future of Children Report, 1996). In addition, chronic conditions such as obesity and asthma are increasing in absolute prevalence (Lollar & Simeonsson, 2005). Advances in medical technology are also reducing high-risk infant mortality rates and increasing the number of children who are experiencing learning, mobility, and quality of life limitations. Msall and Hogan (2007) reported that, "despite the large impact on child health, family life, and economics, research in childhood disability has been woefully inadequate" (p.182). They suggest that this is particularly true for low-income countries and when there is limited public health infrastructure and no formal arrangement between health and education services. Further, they conclude "the key need in survey research and developmental surveillance evaluation is to understand and frame

indicators for social roles at key ages across elementary and secondary school experiences” (p. 183). There has been an increased recognition that early intervention and health promotion efforts are important to reduce or prevent consequences and complications of chronic conditions (Simeonsson, McMillan, & Huntington, 2002). However, adequate surveillance of functional consequences of disease or disability is lacking. Even reliable comparisons of disability prevalence among different countries is difficult due to variability in the type of data collected based on the criteria used to diagnose disabilities, instruments selected to document effects, and age of children studied.

### **Classification of childhood disability**

Classification is both a “conceptual tool” and “means of organizing information” (Florian et al., 2006). Classifications systems have been developed for many purposes, including to rationale for resource distribution, document mortality, and identify children who require additional support services (Florian et al., 2006). The systems are also very much embedded in contemporary perspectives of disability and national priorities for providing support and treatment to children who are not typically developing.

Systems used to document child health status are designed within a particular conceptual framework and reflect assumptions about the meaning of disability. The design of a classification system reflects fundamental assumptions about the nature of development and cause of atypical behaviors or functioning as well as social expectations about children’s behavior and functioning from a particular philosophical stance. The practical importance of the theoretical conceptualization of disability becomes apparent when it influences how and what information is collected for funding decisions.

A standard classification of child health does not currently exist in the United States. However, conceptual changes in childhood classification have “progressed dramatically” over the past few decades (Whiteneck, 2007). A given theoretical model of disability not only reflects how disabilities are viewed in a given society, it also defines what information is necessary to establish a disability and where to direct financial resources for intervention or treatment. Specifically, three important shifts in the conceptualization of childhood disability occurred in the US over the past few decades that were relevant for the design of classification systems. These shifts were reflected in the dominant approach to defining and documenting disabilities within a medical model, social model and functional model of disability.

Categories of disabilities were initially developed within a medical model of impairment, where differences are conceptualized in terms of disease or deficit (Florian, et al., 2006). Child disability was “defined by the manifestation of a health condition in the form of anomalies or impairment of physical or mental structures or function” (Simeonsson, 2006, p. 71). This model was viewed as hierarchical and represented a deficit- based framework where disability is defined as a static problem that exists within an individual (Simeonsson, McMilland & Huntington, 2002). As a categorical approach, the medical model was viewed as “inadequate for documenting the complex and multidimensional nature of disability”, whereby- “assigning a child to a disability category does not lend itself to designing interventions or prevention initiatives”- (Florian et al., 2006, p. 41).

The primary child disability classification system in the United States continues to document problems and summarize symptoms to determine a categorical disability diagnosis. These diagnoses are based on criteria set forth in the American Psychiatric Association

Diagnostic and Statistical Manual of Mental Disorders (DSM), currently the DSM-IV TR.

The purpose and use of the DSM is defined by the American Psychiatric Association as follows:

The DSM is the “standard classification of mental disorders used by mental health professionals in the United States. It is intended to be applicable in a wide array of contexts and used by clinicians and researchers of many different orientations (e.g., biological, psychodynamic, cognitive, behavioral, interpersonal, family/systems). The Diagnostic and Statistical Manual of Mental Disorders, Fourth Edition (DSM-IV) has been designed for use across clinical settings (inpatient, outpatient, partial hospital, consultation-liaison, clinic, private practice, and primary care), with community populations. It can be used by a wide range of health and mental health professionals, including psychiatrists and other physicians, psychologists, social workers, nurses, occupational and rehabilitation therapists, and counselors. It is also a necessary tool for collecting and communicating accurate public health statistics.”  
<http://www.psych.org/mainmenu/research/dsmiv.aspx>

Nevertheless, due to criticism of the medical model, a social model of disability was introduced. The social model offered a perspective of disability as a construct very much influenced by the social expectations and opportunities that exist outside of a child. Within the social model, disability is conceptualized as a social construct, influenced by the attitudes and environments outside of the person (Simeonsson, 2006).

The social and the medical model of disability failed to integrate research on development as a dynamic process occurring through interaction of a developing person and ecological environment. Increasing support for an ecological theoretical perspective of child development (Bronfenbrenner, 1979) provided a framework in which to integrate these two theoretical models of disability. The third model, referred to as a functional model of disability, has recently been introduced and serves as the conceptual perspective reflected in the most recently endorsed World Health Organization family of classifications (Simeonsson,



2006). Assumptions from the medical and social model can be found in the functional model of disability that conceptualizes and classifies childhood disability within a biopsychosocial framework.

The purpose of implementing classification systems has changed considerably during the past few decades, as have the political and scientific conceptual models of disability. Since the 1960s, various measures and systems have been developed to classify childhood development and disability. These efforts were initiated for several reasons, such as documenting mortality and morbidity, establishing eligibility for early intervention or special education services, or designing medical treatment plans (Florian, et al., 2006). Application of the various classification systems has occurred within different professional disciplines and at local, state, and national levels. Civil rights and special education legislation and federal mandates brought about the need to establish equitable allocation of public resources. Although much has been written documenting the failure and areas of bias in the provision of services for children, these changes necessitated the design and implementation of standard classification systems and a shared model of disability.

### **Challenges Classifying Child Health and Disabilities**

The process to identify disabilities varies significantly among countries and within different agencies and professional disciplines. Because of this, it has not been possible to conduct valid comparisons of disability prevalence or to attain sufficient knowledge about cause of variation and differential consequences of a health condition or disability (Florian, et al., 2006). However, comparable and consistent information about child health status and the effects of a health condition or disorder on behavior and development is important for several

reasons. Awareness of discrepancies in measurement, definition, and diagnostic criteria has increased, particularly with the rise in multidisciplinary and interdisciplinary care.

Understanding the consequences and complications that are influenced by person-environment interactions and designing effective programs to prevent secondary conditions begins with research to establish reliable baselines of prevalence rates and data on manifestations of disease or health condition in functional domains (Simeonsson et al., 2002). Because no universal definition of childhood disability exists (Florian et al., 2005; Simeonsson, 2006), collecting reliable prevalence rates and global comparisons of functional outcomes is limited. A lack of reliable global data about the functional consequences of health conditions or variable manifestations of commonly diagnosed disabilities makes it difficult to adequately document and investigate preventable secondary conditions due to a health condition or disease.

Despite these challenges, disability classification and reliance on standardized diagnostic systems have become necessary to attain support in almost every government funded setting. Access to medical, therapeutic, and educational resources is often dependent on meeting specific diagnostic criteria. Children who qualify for services when they meet specific criteria under one diagnostic system may not qualify for services in another setting. For example, a DSM-IV TR diagnosis of ADHD or Autism from a hospital does not automatically qualify a child for special education support services in a school. Likewise, meeting eligibility requirements for special education under a Specific Learning Disability diagnosis does not meet insurance guidelines for support services outside of the educational setting.

The purpose of any classification system needs to be carefully considered so as not to unnecessarily stigmatize or fail to provide needed support services. Historically, classification, categorization, and labeling children has resulted in unintended negative consequences such as stigmatization, lowered expectations, over-identification of different groups, and peer rejection (Florian et al, 2006). While the intent of establishing a standard system to classify children in the United States was based on the need for equitable allocation of limited resources and protection of civil rights, it is important to examine the continued appropriateness and potential unintended negative consequences of the systems used in this process. In addition, there are outstanding questions about the reliability and validity of classification systems and clinical utility regarding informing interventions or the provision of meaningful, evidenced-based services.

### **Limitations of Current Classification Systems**

Promoting the health and well being of children requires identifying areas where altered or compromised functioning is experienced. Yet, obtaining a diagnosis of a disability does not predict child functioning, or inform specific areas to target as intervention outcomes, and very rarely includes important environmental factors as part of the diagnostic criteria (Simeonsson, 2006; Florian et al., 2006). Intervention efforts are not necessarily informed by a diagnosis. Research suggests that assigning a particular diagnosis does not predict functioning or lead to appropriate efficacious interventions (Lollar, 2008). Despite the prognostic information gained with a medical diagnosis of a disease, syndrome, or health condition, criticism has also been made about the lack of information gained from a disability

diagnosis to predict functional outcomes which vary depending the characteristics of the individual child, environmental resources, and experiences (Lollar & Simeonsson, 2005).

Determination of eligibility for services under a federal special education category does little to inform specific classroom interventions or document positive changes in child functioning. Attempts to conceptualize differences among children with and without disabilities, “is a challenging educational problem that defies simple solution” (Florian et al., 2006, p. 41). There are important similarities in functional characteristics among different diagnoses and great variability in the manifestation of a disability within any single diagnostic category (Lollar & Simeonsson, 2005). Yet change in functioning is the primary measure of the effectiveness of interventions and programs, and demonstrating meaningful change has become increasingly important as funding is increasingly tied to evidence based practice (McLaughlin et al., 2006). Although contextual factors are seldom accounted for in the diagnostic criteria of a disability, they are important areas to target for interventions. Additionally, there is increased recognition that differences in experience and modifiable environmental factors influence the specific developmental trajectories of children (Simeonsson et al., 2002).

Evaluating trends, identifying risk factors for functional limitations, and preventing secondary conditions are difficult without standard cross-notational classification system to define and document child health and the effects of disabilities. A lack of a shared framework or service model across professional disciplines also hinders collaboration and integrated service delivery; remedying these differences becomes increasingly important given the expansion of multidisciplinary teams and need for evidence based practice (Lollar & Simeonsson, 2005). The process to document what a disability diagnosis means in the daily

life and functioning of a child is hindered by different definitions and frameworks. Consequently, “the lack of theory and the lack of consistent concepts of disability in childhood have resulted in identification and classification approaches that have been idiosyncratic to disciplines or service systems and taken the forms of diagnoses, syndromes, or categories (Simeonsson, 2006, p. 68)”.

### **International Classification Systems: WHO Family of Classification Systems**

Universal systems of classification began more than 150 years ago with the introduction of the World Health Organization endorsed International Classification of Diseases (ICD) (Lollar, 2008). The purpose of the ICD was to document mortality as well as cause of death and distribution of disease. The ICD has undergone several revisions since it was first introduced, with the 10<sup>th</sup> revision approved in 2005 (Florian et al., 2006). This system is still used in the United States (ICD-9) as the standard for medical care disease and disorder classification with health insurance funding dependent on the assignment of an ICD code. Florian et. al. (2006) suggests that “recent developments in the ways in which disability is being conceptualized have resulted in new international classification systems that challenge traditional ways of thinking about categories and labels (p.36)”.

The need to understand the consequences of disease or health conditions, prompted the development of the International Classification of Impairments, Disabilities, and Handicaps (ICIDH) by the WHO in 1980. Moving beyond a single category diagnosis, the ICIDH was piloted as a research classification measure (Lollar & Simeonsson, 2005). This new taxonomy introduced an important paradigm shift in the way that disability was viewed because the effects of an underlying health condition were documented. In addition, the

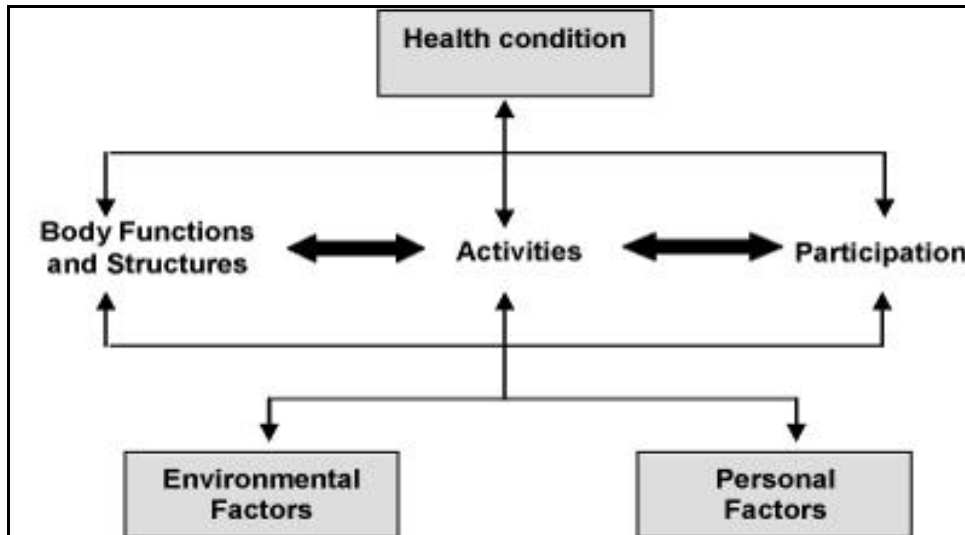
consequences of a health condition on a person's daily functioning were conceptually represented by three different levels (i.e., impairment, disability and handicap).

Although the ICIDH greatly contributed to the changing model of disability, the application of this system was limited and since it was intended to serve as an experimental tool, it was not widely adopted (Florian et al., 2006). Further, the framework of disability continued to emphasize a deficit perspective as inherent within an individual and this conflicted with emerging views about disability from a social perspective. In the 1990's, experts began revisions of the ICIDH, building on the implementation and integrating emerging models of disability. After a decade of international collaborative efforts on the revision, the International Classification of Functioning, Disability, and Health (ICF) was created; it serves as the current standard taxonomy of adult health and disability.

**The ICF.** The International Classification of Functioning, Disability and Health (ICF) is the WHO's current framework for health and disability. It reflects a functional model of disability and therefore was intended to emphasize the level of health and daily functioning rather than the person's disabilities. The ICF integrates components of the medical and social models to address biological, individual, and social perspectives on health to use a biopsychosocial model of disability (Peterson, 2011). The ICF provides a holistic view of human functioning.

The ICF aims to provide a unified and standard language and framework for the description of health and health states based on the dimensions of functioning at the body functions and structure level, with activities at the individual level, and participation in society (Granlund, Erikson & Ylven, 2004). The ICF expansive set of codes are intended to document profiles of functioning at the body, individual, and societal levels (Simeonsson,

Scarborough, & Hebbler, 2006). The ICF classification system was guided by a biopsychosocial model and represents the interaction of four major health components (Stamm & Machold, 2007). It therefore addressed the need for a conceptual model that recognized the role of environment and social dimensions of disability (Simeonsson et al., 2003). The domains included in the ICF are conceptually linked as displayed in Figure 1.



*Figure 1. ICF Conceptual Framework*

The ICF represents important changes to the current perspective of disability. The ICF focuses on positive aspects of health, rather than only consequences of illness or disability. As such, "...the way we think about health and disease determines to a considerable extent what we do and say in our clinical encounters with patients, and the ICF represents an exciting new way to consider health and disease" (Bruyere, Van Looy, & Peterson, 2005, p.115). The taxonomy provides descriptions of health rather than disease and attempts to use value neutral language. Further, the underlying assumption that disability is a universal phenomenon and manifestations of a health condition or disability are a consequence of interactions among the body, personal, and societal levels supports a

functional model of disability and encourages consideration of the role of environmental factors in mediating functioning (Lollar & Simeonsson, 2005).

The ICF includes more than 1400 categories that are sub-classified into the four major domains. The categories are neutrally defined, such that disability is indicated only when a severity qualifier is applied to the code to document the extent of impairment (at the Body Function and Body Structure) or level of limitation or restriction (in the Activities and Participation domains). The factors in the Environmental Domain can be coded as either facilitators or barriers to functioning.

The structure of the ICF includes lettered and numbered codes organized in four levels representing increasingly detailed categories. Specifically, the ICF components begin with a letter identifying the domain and include a series of numbers representing chapters, category, and subcategories (i.e., letters are b-body functions, s-body structures, d-activities and participation, and e-environmental factors). Each domain includes multiple chapters (first level) that contain categories (second level), which become more specific (third level categories) and some become even more detailed categories (fourth level). Qualifiers ranging from 0-4 can be applied to the categories to denote level or severity of a problem, limitation, or restriction for functioning across the four components (i.e., from 0=no problem, 1=mild, 2=moderate, 3=severe, 4=complete) (WHO, 2007).

***ICF Contributions.*** The contributions of the ICF in promoting a standard classification of health and disability are immense. As a companion to the ICD-10, the ICF encourages the documentation of the multidimensional aspects of health and consequences of underlying health conditions. Including environmental variables as important aspects to document reinforces the need to view functioning and disability in context. Within the ICF



biopsychosocial perspective, “the patient’s functioning is conceived as a dynamic interaction between the underlying health condition and specific personal and environmental contextual factors” (Tschiesner et al., 2007, p.1216).

The publication of the ICF (WHO, 2001) has resulted in applications in various health fields (Stucki & Grimby, 2004; Institute of Medicine, 2007; Walsh, p.2004). The ICF has become the international conceptual basis for definition, measurement, and policy formulations for adult health and disability. It has multiple purposes such as use in policy planning, surveillance, and documentation of intervention outcomes. The ICF can be used to document consequences of health conditions, establish common language to improve communications, and facilitate reliable comparison of data across countries, health care disciplines, services and time. Also, the ICF can provide a systematic coding scheme for health information systems.

The utility of the ICF has been tested in several studies through the EU project MHADIE: measuring health and disability in Europe: supporting policy development. There are 16 European Centers and 10 different countries that participate in this group. After conducting a thorough review of ICF applications during the first three years after WHO endorsement, Bruyer and colleagues (2005) concluded, “numerous authors support the ICF framework and its utility for rendering comparable health information from multiple settings, across various applications, and across countries” (p. 114). In addition, they found support for the hypothesis that the collection of functional status information could facilitate more effective evaluation of treatment outcomes and comparisons of treatment approaches. Another important contribution was that the ICF promoted the recognition of environmental factors in all aspects of health and functioning

**Rationale for a Child and Youth version of the ICF.** The ICF made several important contributions to the current model of disability and approach to documenting and classifying health and daily experience for individuals with chronic health conditions or disease. However, it did not specifically address children or adolescents. The ICF designed for adults was not sensitive enough to capture the rapid developmental changes and unique dimensions of childhood as well as the specific contexts such as home and school that profoundly affect child development. As summarized by Lollar (2008) a derived version of the ICF specifically for children was needed because capturing disability status or health status for a child is complicated given that development proceeds rapidly and is a dynamic process influenced by ongoing interactions with other people and environmental factors that can promote or impede development.

Additionally, some content representing functional areas particularly relevant for children were missing, such as codes to capture learning and play (Lollar, 2008). There was also an identified need to distinguish impairment or deficit from delay as the rate of development across domains for children varies. Therefore a new classification system derived from the ICF was developed for use with children. New codes were added to expand the ICF content and increased specificity for items that represent developmental aspects and changes in body structures, body functions, types of activities, and participation differences for infants, children and adolescents (Simeonsson, 2009). Recognition of the unique, rapid, and substantial developmental changes that occur over the first two decades of life is reflected in the differences in suggested use and item content between these classification systems (Simeonsson, 2006).

## **ICF-CY: A Health Classification for Children and Youth**

The International Classification of Functioning, Disability and Health-Children and Youth (ICF-CY) is the first standard international taxonomy of health and disability designed exclusively for children and youth (WHO ICF Manual, 2007). Until the ICF-CY, no previous classification effort sought to unify documentation and measurement of child development and health using a universal language and conceptualization across disciplines and countries. The ICF-CY includes categories that describe social, educational, and functional needs of children as well as medical needs (Ibragimova et al., 2005).

Consistent with the ICF, the ICF-CY codes are organized into the Body Structures, Body Functioning, Activities and Participation, and Environmental Factors domains. The ICF-CY provides a comprehensive taxonomy to classify functional characteristics of individuals across these domains (Simeonsson, 2009). Under each major area there are several chapters delineated into subsections of characteristics that each contain increasingly specific detailed criteria of functioning and health. Numeric severity qualifiers from 0 (none) to 4 (complete) can be applied to the body, person, or societal dimensions to document problems and classify consequences of a disability within an ecological framework. The codes and qualifiers together capture the extent or magnitude of problems, delays, or changes in functions, body structures, and performance of activities for a child. Unlike the ICD where one final diagnostic code is selected, the ICF-CY provides an array of codes and produces a profile of a child's current functioning.

The ICF-CY is also the first unifying framework to describe effects of environmental factors on child functioning, which “can be a significant contribution to the practice and science of work with children and youths” (Lollar & Simeonsson, 2006, p. 326). It provides a

common language and universal lens with which to view and investigate the dynamic process of child development using an ecological framework guided by United Nations Rights of the Child and is the “first internationally agreed upon classification code for assessing the health of children and youth in the context of their stages of development and the environments in which they live” (WHO ICF-CY Manual, 2007, p. 1).

### **Early Applications of the ICF-CY**

The ICF-CY was designed as a universal system to document health and classify developmental characteristics of children to provide a standard conceptual framework for use by clinicians, researchers, and policy makers across professional disciplines. Support for integrating the ICF-CY into policy and practice is increasing both domestically and abroad. International research efforts aimed at documenting prevalence and impact of disability using the ICF-CY have also begun. In the European Union there are new national policy initiatives that will mandate the use of the ICF-CY in the provision of special education service (e.g., 2008 Portugal). The ICF-CY has also been used for surveillance of student functioning (Qatar). In the United States, the ICF-CY is gaining visibility through endorsement from various national professional organizations and government agencies (e.g., American Physical Therapy Association (APTA); American Public Health Association APHA). In addition, the American Psychological Association is currently developing a practice manual for the ICF (Simeonsson, 2009).

**Field trials of the ICF-CY.** Field trials of the ICF-CY were conducted from 2002-2004 by the ICF-CY workgroup. During this time a multidisciplinary research group at Mälardalen University in Sweden conducted a series of implementation and feasibility

studies of the ICF-CY. Studies conducted by researchers in the CHILD (Children-Health-Intervention-Learning-Development) group included investigating perceived difficulties or benefits using the ICF-CY model for interventions, examining content validity, and evaluating ICF-CY usefulness for documentation in service delivery. Studies conducted in Sweden using the 2004 ICF-CY draft examined the reliability and validity of the ICF-CY. Analysis of reliability found adequate to very good levels of consistency. Content validity was also examined. Factor analyses were performed to examine construct validity regarding factor structure of the ICF-CY categories and found variable consistency and some overlap between chapters (Ibragimova et al., 2005).

In 2004, field trials of age-based questionnaires (i.e., younger than 3, 3-6, and 7-12 years) were conducted at Mälardalen University in Sweden (Ibragimova, Bjorck-Akesson, Granlund, Lillvist, & Eriksson, 2005). Professionals were recruited to go to the university website to download and complete a questionnaire for a child. These questionnaires were designed to be consistent with the organization of the ICF-CY. These questionnaires included at least one item from every Chapter in the ICF-CY and directly related to specific ICF-CY codes. The questionnaires were adapted to children in the three age groups. The research team examined 130 checklists from professionals in special education, physiotherapists, occupational therapists, psychologists, social workers, speech and language pathologists, physicians, and nurses. The study respondents indicated that they referenced journals, direct observations, and interviews to complete the questionnaires.

According to investigators, participants reported that the ICF-CY questionnaires were difficult to complete, and noted the most difficulty with body structures and environmental factor items. Challenges using the ICF-CY questionnaires also included lack of knowledge

about the ICF-CY, time to complete the questionnaires, difficulty completing with parents in direct conversation, unclear definitions of some codes, and the need for clarification about how to apply qualifiers. Nevertheless, clinicians indicated that using the ICF-CY to describe children in specific age groups was meaningful, and identified the questionnaires as useful in teamwork and for describing children from another cultures. The overall utility of the ICF-CY questionnaires was determined to be good for providing an overview of children's problems. In addition, more than half of the respondents reported that they wanted to use the questionnaires again in their practice (60%) and viewed the questionnaires as useful for intervention planning and facilitating communication among professionals.

In general, findings from the 2004 Swedish field tests of the WHO developed age based ICF-CY questionnaires indicated that professionals found the questionnaires useful, but comprehensive and difficult to apply in clinical practice. Thus, in 2005 the I-CY-HAB project was initiated at Mälardalen University to revise the ICF-CY questionnaires based on participant feedback during the field trial. Reduced item forms were developed and organized by ICF-CY domain and used to examine the utility of the ICF-CY within Swedish habilitation services (Adolfsson, Pless, Ibragimova, Granlund, & Björck-Åkesson, 2007). Prior to using the I-CY-HAB forms, clinicians participated in a training that appeared to facilitate the application and understanding of the ICF-CY forms. The items in the I-CY HAB Forms contain a reduced number of items determined to be necessary in clinical work. Items represented on screening questionnaires and interviews were found to be important to clinicians, but still represent a tool that was difficult to use in practice because of the length (i.e., 134 codes at the Activity and Participation, Body Function and Environment domains).

Field trials and current research suggests that the ICF-CY's usefulness for documenting child characteristics in early childhood intervention and habilitation services looks promising. After presenting a review of studies examining the conceptual model and application of the ICF-CY in Sweden, Björck-Åkesson et al., (2010) concluded, "results indicate that instruments based on the classification can provide a reliable, valid, and clinically meaningful description of functional status, taking into account clinical and everyday environments" (p. S136).

Recently, attention has been toward mapping items from reliable and valid measurement instruments. For example, researchers in Sweden have conducted preliminary studies to inform the design of an interdisciplinary assessment tool of child participation in daily life situations (Adolfsson et al., 2010). A systematic review of the literature found few measures of child participation or performance (i.e., 12). An analysis was conducted to examine the content of available measures and subsequently align items in measures to ICF-CY codes. Linking rules described by Cieza et al. (2004) were applied; these have been used with ICF Core Sets. The intent of classifying child characteristics with the ICF-CY is not to yield a diagnosis, although standard measures can be mapped to items in the ICF-CY and assessment measures based upon the ICF-CY conceptualization and categories are in development.

### **Challenges using the ICF and ICF-CY**

Despite the universal support and conceptual agreement for the ICF, the following two significant challenges for implementation remained: low familiarity with the new approach and the large number of categories included in the system (Tschiesner et al., 2007).

Professionals across disciplines such as nursing, occupational therapy, and speech language pathology generally found the ICF useful, although limited in its practical clinical use, given the high level of detail needed for specific treatment (Bruyere, et al., 2005). Initially, the ICF was primarily used as a conceptual framework in research and for recording data from standard measures and health classifications. However, professionals reported that the functional descriptors used in the ICF would increase understanding about important characteristics of children with special health care needs and chronic conditions.

**ICF Core Sets.** While the comprehensiveness of the ICF as a classification system is considered an advantage and strength, it has also been recognized as a “major challenge to its practicality and use in clinical practice” (Stier-Jarmer, 2009, 30) and prompted the creation of reduced lists of ICF categories for use with individuals who have a particular chronic health condition. The reduced item sets are referred to as “Core Sets”. Additional ICF categories can be added, but core sets are comprised of select ICF categories that are intended to represent a minimum standard for clinical work and research for a specific health condition or disorder. ICF Core Sets have a brief and comprehensive version. The Brief ICF Core Sets have “as few categories as possible to be practical, but as many as necessary to sufficiently describe the typical spectrum of problems in functioning of patients” (Stier-Jarmer, 2009, p. 30). They serve as a standard for reporting of clinical studies and are designed to characterize a specific condition or confirm a diagnosis.

There are 15 ICF Core Sets for chronic conditions that were created following a standard international consensus protocol developed by the ICF Research Branch of the WHO FIC CC (DIMDI), WHO Classification, Assessment and Surveys (CAS) team, and Ludwig-Maximilian University in Munich with support from different international societies



(Stier-Jarmer, 2009). The ICF Core Set Project was initiated by Professor Gerald Stucki in 2001; the ICF collaborative workgroup developed core sets from the for the following chronic conditions: Low Back Pain (LBP), Obesity, Stroke, Depression, Breast Cancer, Chronic Widespread Pain, Osteoarthritis, Osteoporosis, Rheumatoid arthritis, Chronic ischemic heart disease, Diabetes mellitus, Obstructive pulmonary diseases, Head and neck cancer, Multiple sclerosis, and Spinal cord injury (Stucki et al., 2003; Tschiesner et al., 2007). The aim of the project was to make the ICF feasible and easy to use in clinical settings, as well as provide assurance that rehabilitation services are provided consistently to support patient care.

The design of the 15 ICF Core Sets followed a similar process. The Delphi technique was used to reduce the ICF content to key characteristics or classification indicators based on particular common adult diseases. Each started with a systematic literature review to inform the creation of a survey that was administered to experts in that particular condition. The Delphi survey method was used to collect data. Findings from the Delphi surveys were validated using focus groups. For some core sets the focus groups were conducted at multiple facilities and with patients while other core sets were validated by focus groups with experts at collaborative work group meetings (Stuki et al., 2004; Stier-Jarmer, 2009).

The ICF Core Sets have been demonstrated as useful for outcome and rehabilitation research, clinical practice, and health status (Stier-Jarmer, Cieza, Borchers, & Stucki, 2009). They can be used for multiple purposes. For example, Cieza et al., (2004) directed the derivation of core sets for Lower Back Pain. The aim was to maintain adequate coverage of areas that should be assessed for patients with low back pain so that a comprehensive picture of presenting problems and context can be obtained and provide the basis of functional areas

that should always be measured. Personal history, symptoms, and problems can be documented within this multidimensional framework and information collected can serve as a baseline to guide treatment and outcome evaluation. Rather than searching for appropriate items from 1400 possible options, reduced category or item sets (“core sets”) direct clinicians and researchers to identified items to describe functioning for specific populations. Thus, ICF Core Sets become a standard classification tool that can be used worldwide to increase knowledge about specific conditions and facilitate reliable comparison of treatment. In addition, content comparisons of Health Status measures have been performed to further validate the ICF LBP Core Sets. Linking items from valid and reliable existing measures can help standardize items and instruments and facilitate the creation of an “item bank” for studying latent variables (Stier-Jarmer, 2009).

**Challenges applying the ICF-CY.** Although there are vast implications for the ICF-CY in clinical care, research, and policy, the application of the ICF-CY remains difficult. Lollar & Simeonsson (2005) identified two existing problems in applying the ICF-CY to clinical practice. First, codes in each ICF dimension need to be cross-referenced with current measures of child functioning. Second, time and resources necessary to complete all codes of interest for a particular child are often limited. The ICF-CY is comprised of numerous potential characteristics to code. It is an expansive multidimensional classification system of functioning at the body, personal, and societal levels for children birth to seventeen years of age. Coding the most salient dimensions of functioning or most useful information and deciding who should collect this information has been identified as important for the successful application of the ICF-CY in clinical settings (Lollar & Simeonsson, 2005).

## **Rationale and Study Purpose**

The purpose of this study was to enhance the utility of the ICF-CY in clinical and research settings by deriving four ICF-CY Developmental Code Sets representing essential dimensions of child functioning based on consensus from an international sample of multidisciplinary experts. Professionals from all major regions of the world participated in a three-round Delphi procedure, prioritizing ICF-CY codes for four different age groups. Specifically, developmental code sets were created for children (a) birth until three years of age, (b) three through five years, (c) six through twelve years, and (d) thirteen through seventeen years in a method that maintained structural continuity with the ICF-CY. The aim was to develop brief code sets that are applicable within a global and multidisciplinary context to document child functioning and disability in research, clinical practice, and policy.

Efforts to facilitate the acceptance and application of the ICF-CY process are timely and necessary given the enormous benefits that are possible. This advancement requires rallying support from professionals nationally and internationally and making the ICF-CY as user friendly and meaningful as possible. Given the extensive scope of the ICF-CY, the clinical feasibility and ready integration of this important tool into research and policy is restricted. Specific limitations in the use of the ICF-CY might be the time necessary to decide which indicators need to be coded, the lack of general understanding about the purpose of ICF-CY, or even limited knowledge about availability of this classification system (Lollar, 2008). Findings from the proposed study will address these challenges and thus are expected to increase the utility of the ICF-CY.

Promoting the ICF-CY as a framework for clinical practice requires that the ICF-CY should be “consistent with existing values, existing knowledge, easy to understand, learn, use, and to obtain results from” (Björck-Åkesson, 2010, p. S134). In order to use the ICF-CY

for clinical documentation as a universal approach for classifying child functioning and disability, it would be helpful to reduce the content to a limited number of codes that would be of importance for a particular purpose (Simeonsson, 2009). The brief list of limited indicators would serve as a common starting point for what is assessed and documented clinically.

The ICF-CY indicators are expected to represent the most salient dimensions of functioning for children and youth according to national and international experts. Reducing the potential codes for research or practice by developmental expectation, according to age, would streamline the use and improve the feasibility of this tool in clinical practice and research. Thus, the results from the current study are anticipated to promote the ICF-CY and enhance feasibility of the ICF-CY.

## **CHAPTER 3**

### **Method**

A multiple-step Delphi survey technique was used to derive the four age-based developmental code sets. Participants were asked to complete a series of online surveys to identify essential indicators of child functioning and disability from the WHO ICF-CY. Participants ranked items from the Body Function, Participation and Activities, and Environmental Factors domains of the ICF-CY. Three rounds of questionnaires were administered to build consensus, with the second and third surveys designed based on the results from previous surveys such that the number of items ranked was reduced at each wave of data collection. Background information and previous experience with the ICF-CY was obtained in the initial questionnaire. The final questionnaire presented the four derived item sets and requested a final review, feedback, and endorsement from the sample.

The Method chapter is divided into four sections. The first section describes the study design and measures used in the study. The second section describes the sample selection. The third section outlines the data collection process. The fourth section presents the data analysis procedures used in the study.

### **Study Design**

Data were collected using the Delphi survey technique. The Delphi technique or procedure is a research method that uses an iterative multistage process to facilitate agreed upon expert opinion into group consensus (Hasson, Keeney, & McKenna, 2000). The aim of

the Delphi process is to achieve group consensus from a purposeful sample of experts from individual surveys so that responses are anonymous and any influence by other group members is minimized. The Delphi procedure was developed in the 1950's by the RAND Corporation for an Air force sponsored study "to obtain the most reliable consensus of opinion of a group of experts" (Linstone & Murray, 2002); it has since been used in numerous fields including rehabilitation, education, medicine, nursing, and information technology fields. It is considered a "structured communication process" that involves the following four key characteristics: participant anonymity, iteration with controlled feedback, statistical group response, and expert or informed input (Morita, Weigl, Schuh, & Stucki 2006, p.184; Finger, Cieza, Stoll, Stucki & Huber, 2006).

Several variations in procedures have been described in the literature regarding sample selection of experts, size of expert panel, and the definition used to determine consensus (Biondo, et al. 2008). Although there are no "formal, universally agreed upon guidelines" (p. 16) to apply the Delphi method, design decisions for the present study were guided by health and social science studies that successfully used the Delphi technique including ICF Core Set studies. Specific references used to guide design decisions are included within the following sections that delineate sample selection, data collection, and data analysis procedures.

Common data collection procedures for the Delphi procedure found across studies include ascertaining anonymous individual feedback, analysis of group data between data collection rounds, and providing participants an opportunity to revise or review previous

responses. These general principals provided a general framework for the study design. In addition, common problems identified in the literature were considered during the study design process to prevent or reduce bias and strengthen reliability. Problematic areas that were identified include restrictive group selection, lack of honesty in analysis or misrepresentation of summarized information, and misunderstanding questions or language by a culturally diverse group of participants.

The Delphi procedure was determined to be an appropriate research method for several reasons. First, this procedure has been successfully used to develop several ICF Core Sets for adult medical conditions or disease (Stucki et al., 2003; Stier-Jarmer et al., 2009). The design of the proposed study follows a similar process used to develop ICF Core Sets without the third stage involving item validation using focus groups (i.e., starting with a systematic literature review then initiating a multiple round expert survey using the Delphi technique). Thus, a thorough review of the ICF Core Set research was conducted to guide the design and implementation procedures used in the current study.

Second, the Delphi technique is a relatively inexpensive research method that would allow efficient recruitment of experts located in diverse settings and residing in various countries. Third, it is a versatile research method that enables participation of a vast number of geographically dispersed individuals at a time convenient to the participant. Using a flexible and affordable approach that allows global participation was essential, given the primary goal of the study that is to achieve expert consensus of developmental code sets from representative national and international researchers and clinicians who are the intended

consumers of the WHO ICF-CY. Finally, an online format was used to collect the data because it allows the immediate analysis of data required between each round of data collection. Specifically, an established web-based company (i.e., SurveyMonkey) was selected because it offers data security, allows for sample confidentiality, and readily documents participation status linked to email addresses for management of follow up and response rate.

### **Instrument Design**

Original surveys were designed for each round of data collection. Second and third round questionnaire content was determined after an analysis of participant responses to a prior survey. The following sections describe the design of each questionnaire by data collection round. As noted previously, the goal of the study was to derive reduced item ICF-CY code sets which represent universal indicators of key dimensions of health and expected child functioning at four different age ranges from the existing ICF-CY codes. Before asking participants to rank the importance of items as essential to include for each developmental code set, it was necessary to determine if ICF-CY codes could be meaningfully grouped according to developmental expectation or age range by a diverse sample of experts. Therefore, survey one items were organized under ICF-CY domains rather than by proposed age range.

**Survey Design Round One.** The first online survey was intended to collect background information about the study sample and determine if the selected ICF-CY



categories could reasonably and meaningfully be separated into developmental or age based item sets. As there are more than 1,600 codes in the ICF-CY the design of the initial survey was informed by the findings from extensive field trials and pilot studies that examined select ICF-CY second and third level codes. Consideration was given to balancing adequate breadth of areas covered and reasonable completion time to minimize investigator bias through the initial exclusion of ICF-CY items and maximize sample recruitment and retention. Therefore identifying items in previous research that were critical to include in research or practice for participants from diverse backgrounds was an important step in designing a universal questionnaire.

To that end, the design of the first questionnaire was informed by the field trial work of ICF version for children and youth (ICF-CY) in Sweden and included items from the I-CY-HAB Forms 1-3 developed at Mälardalen University (Björck-Åkesson, Granlund, & Ibragimova, 2005; Adolfsson, Pless, Ibragimova, Granlund, & Björck-Akesson, 2007). As described in the literature review, reduced items sets were designed based on findings from the 2004 field trials of age-based questionnaires in Sweden (i.e., younger than 3, 3-6, and 7-12). The I-CY-HAB Forms were developed by ICF-CY domain (i.e., Body Functions, Activities and Participation, and Environmental Factors) and used to increase the utility of the ICF-CY within Swedish habilitation services (Adolfsson et al., 2007). Permission was obtained from primary investigators in Sweden to use items from the I-CY-HAB forms in the first online survey. These items were included in the online questionnaire with select additional ICF-CY codes based on a review of the ICF-CY and knowledge of developmental

literature. The I-CY-HAB forms contained 134 codes at the Activity and Participation, Body Function and Environment domains. These items were cross-referenced with the first questionnaire and the simplified wording in the I-CY-HAB was used when available to help clarify code definitions in the present study.

The first survey included 142 second and third level items from the ICF-CY Body Functions, Activities and Participation, and Environmental Factors domains and participants were asked to examine each of these for possible inclusion in the four developmental code sets. All items were included for each of the four age groups. Participants were asked to consider whether an item applied to a particular age group, and if so, was essential to include in the standard reduced item set for the age group that could serve as a minimal set for reference in research, policy or clinical applications with children. While the inappropriateness of some items for an age group seemed apparent, it was important to allow the participants to determine code relevance through an iterative consensus building process.

In addition, because the ICF-CY is designed for worldwide use in various professional settings and by different disciplines, it was important to document the national and professional diversity of the study sample. Initial items asked participants to provide background information about their professional discipline, nature of their work, years of experience, educational attainment, primary country of residence, and current involvement in international work.

The first survey was reviewed by the advisor of this dissertation, who co-chaired the WHO ICF-CY design workgroup and is an international expert in the field of child

psychology. It was then piloted with a select group of professionals and graduate students to determine respondent burden, instructional clarity, and comprehensiveness of content coverage. Specifically, two graduate students (one from the United States and one from Sweden) and a professor in speech-language pathology who was knowledgeable about the ICF-CY completed the field test version of the questionnaire in February 2010 using the SurveyMonkey program online format. Feedback was solicited for completion time, clarity of instructions and items, survey format, program use, implementation concerns, and content.

Overall, the survey content and format appeared to be appropriate, but the completion time was too long, taking some responders more than an hour. Efforts were made to minimize completion time by limiting the scope and length of questionnaires, revising response category options, and allowing participants to complete the questionnaires from any setting at multiple times if needed respondents were informed that they could chose to save responses for part of the survey and then return at another time to finish.

The first survey was redesigned after piloting to minimize respondent burden, particularly because participation was voluntary and no monetary incentive was provided. In the revised questionnaire format, participants were asked to indicate for which of the four age groups, if any, the items would be appropriate to include in the code sets in a checklist format selecting only the endorsed items, rather than provide a relative ranking or have to indicate yes or no for each item.

**Second Round Survey Design.** Subsequent iterations of the survey included only items where consensus was reached, along with an opportunity to suggest items that were

dropped or excluded. The second survey questionnaire was designed according to the responses obtained on the first survey. Specifically, items that were indicated by at least 75% of the sample as appropriate or important to include in a given age-based code set were brought forward to the second round. For the second round of the survey, only items that were endorsed by at least 75% of study participants were included. The items were also arranged by age group, rather than ICF-CY domain.

Participants rated each item under the specified age groups as essential, very important, or somewhat important to include in the developmental code set. Participants were asked to consider the relative importance of the items as part of ICF-CY universal minimal item sets for reference in research, policy or clinical applications with children. The survey also included an open-ended question to allow participants to comment on items that should still be included that did not reach inclusion criteria. Prior to sending the second survey, the dissertation advisor and another doctoral student knowledgeable about the ICF-CY reviewed the items and questionnaire and provided feedback about general format and specific items.

**Third Round Survey Design.** The final survey was created based on the items indicated by the majority of the sample as essential to include in the developmental code sets at the second round of data collection. Specifically, ICF-CY items for the domains of Body Function/Structures and Activities and Participation that were rated as essential by the majority of participants (i.e., over 50%) were included in proposed code sets in the third survey. Consensus lists of ICF-CY codes were presented to participants to review for inclusion in final developmental code sets. Participants were asked to indicate if items meet

the study criteria for derived code sets that define essential features of functioning and disability in children within the four each age groups and rate quality and coverage of items. Participants were provided an opportunity to provide feedback about the item sets and indicate specific items that they did not agree with for inclusion.

In sum, the first survey started with 142 items for each age group. Codes endorsed as appropriate and important to consider for age based code sets during the first survey by at least 75% were included in the second iteration of data collection. Participants were asked to then evaluate relative importance for inclusion in final sets. Items from the second survey rated as essential by the majority of participants (i.e., over 50% of the respondents) were included in the third round questionnaire.

### **Data Collection Procedures**

A primary goal in this study was to develop internationally recognized code sets of the ICF-CY classification system that are applicable in a range of practice settings and countries. Therefore, sample selection and recruitment were important preliminary data collection activities. The following section describes sampling procedures and provides detail regarding the data collection procedures outlined in the previous section on study design.

**Sample Selection.** To obtain valid and meaningful results using the Delphi procedure, consideration must be given to the composition of the expert panel so that adequate representation is achieved upfront (Campbell, Shield, Rogers, & Gask, 2003). Because the Delphi procedure calls for a purposeful sample of experts no randomization was expected;

however, it is important to include individuals who reflect the audience or represent stakeholders for whom the information is intended. For this study, the sample of experts was selected based on the following criteria: established national and international experts in content knowledge determined by quality and extent of publications and professional associations representing diversity of discipline and country of origin. As such, efforts were made to recruit professionals from fields of psychology, physical therapy, speech-language pathology, medicine, education, and occupational therapy who also represent a range of cultures as well as program administrators and directors of agencies that serve children with disabilities or chronic illness. In addition, particular attention was given to include a number of experts who were already familiar with the WHO international family of classification systems and assisted with the creation of the full ICF-CY.

Thus, participants in this study were purposefully recruited to represent intended consumers of the WHO ICF-CY. The ICF-CY was designed for international use as a common framework for professionals across disciplines. Therefore, national and international professionals were selected to represent diverse professional fields and areas of content knowledge. Although consideration was given to the inclusion of families or children who represent other intended consumers of the ICF-CY, the decision was made to define the scope of the sample to practitioners, researchers, academic faculty, administrators, and professionals in training in psychology, physical therapy, speech and language pathology, occupational therapy, medicine and education.

**Sample Recruitment.** Sample recruitment efforts aimed to build a sample of 100 professionals and consumers of the ICF-CY. Although no set criteria has been established for determining a Delphi sample size, recommendations in peer reviewed publications call for at least 10 panel members (Keeney, Hasson, & McKenna, 2005). The sample size was selected because the scope of this study will cover development for children of all ages, across different disciplines, and representative of several countries. Thus, initial efforts aimed to personally invite 100 individuals by email.

The initial sample list was formed by nominations from the dissertation committee and suggested contacts with prior involvement and demonstrated interest in the ICF-CY as identified by the dissertation advisor. The dissertation advisor and committee members provided contact information to help identify individuals as needed. In addition, individuals recruited were encouraged to nominate other professionals or advocates who met sample criteria. Internet access and an email account were necessary to be eligible for study participation as this was the mode of initial contact for study recruitment. Individuals who agreed to participate were sent official study invitations that included a description of the process and informed consent procedures.

Invited participants were asked to either share names of eligible participants or forward the initial email describing the study. In addition, a posting was made to the International Society in Early Intervention (ISEI) because this organization represents a global sample of experts who were all recommended for inclusion in the professional organization by members. Efforts to add more international participants were important to

assure adequate representation of several countries and diverse perspectives because this is the aim of the ICF-CY. Participants had to be at least 18 years of age (i.e., adult status). Given the interest in joining an international professional group, it was hypothesized that these individuals would also share a strong interest in collaborative, international research and ICF-CY application. Interested ISEI members were asked to email the author to indicate interest in the study and were then told they would be sent the official study email invitation.

Individuals were invited to participate with an email that explained the purpose and process of the study. According to procedures approved by the University of North Carolina, Chapel Hill IRB all sample participants were required to reply to the official detailed invitation. Informed consent was obtained when eligible participants replied to the email indicating that they were willing to participate in the study. Recruited participants were provided with a description of the study, assurance of confidentiality, and informed about potential risks and benefits to participating. Participants were offered a copy of the final code sets for use in practice, research, and policy endeavors. Those individuals who did not want to participate or receive future contacts were removed from the web program email distribution list.

After responding to the official email invitation, the study sample was sent a link, via email, to access and complete an online survey. Each person who agreed to participate was assigned an individual code and that was linked to their email address in the SurveyMonkey online system. The link to the online survey was connected to a specific email address so that follow-up email reminders and subsequent surveys would be consistent. Follow-up reminders



were sent based on the status indicated in the web programs. Individual emails were sent to study participants between data collection rounds with attached documents in PDF files of the summary of participant responses and their own responses to questionnaire items to compare or review before receiving a link for the next online survey.

**Sample retention.** Efforts to maintain the sample included email reminders as well as a summary of survey results and corresponding personal responses after the first and second survey data collection round. Recruitment and retention are issues that have been addressed in recent Delphi methodological literature (Keeney et al., 2005; Mullen 2003). A review of literature does not yield consensus on minimal response rate. Strategies that are recommended to retain participants include providing clear information about the study and time commitment prior to the first round questionnaire. Thus, efforts employed to increase response rates and retention between rounds included the following: obtaining participant buy-in, limiting time demands, providing direct and upfront expectations about the time involved for completing all necessary rounds, and explaining potential risks and benefits for participation. A summary of the results between survey rounds was also sent to those participants who did not complete a survey in an effort to facilitate participation in a future round. In addition, follow-up reminders were sent based on the status indicated in the web programs, with non-responders and partial responders sent different email reminders.

## **Data Analysis**

Obtaining expert consensus of essential items occurred in successive steps. In the Delphi technique, information is analyzed between each round and participants are provided controlled feedback to allow panel members an opportunity to reconsider or re-rate their opinions (Chou, 2002). Thus, analysis of data for this study occurred after each round of data collection. Descriptive statistics as well as percent agreement on each item were obtained. Open-ended comments were coded using qualitative content analysis procedures. To determine consensus for ratings of the round one questionnaire, a 75% cut off was used as this has been found to clearly differentiate the consensus and non-consensus results of previous research. In fact, 80% has been commonly used with ICF core set development but this cut off point was “selected for practical reasons, and it still remains to some extent arbitrary and therefore can be criticized” (Finder et al., 2006). Data was also examined at the 80%, 75%, 70%, and 60% agreement points to determine if any systematic problems were evident at the set 75% agreement level. No remarkable differences were noted.

The responses from the first questionnaire were summarized and returned to experts for further consideration in a PDF file. The data were summarized and the anonymous results of the panel and individual responses were distributed before administration of the round 2 questionnaire. Participants were asked to rate the second survey items on a three point scale. The ratings were analyzed for consensus and percent agreement. Open ended questions about developmental domains based on age were examined using content analysis procedures and a summary of this information was included in the second questionnaire. Final code sets were distributed to the group, and panel members had a final opportunity to provide comments or

feedback about the content determined by group consensus. Additional analyses were conducted to examine bias by identified national residency. In addition, data were examined for retention rates of items by code set, representation by ICF-CY domain, and overlap of specific items among the four age groups.

## **CHAPTER 3**

### **Results**

The Delphi technique proved to be a valuable and efficient method for obtaining expert consensus on essential ICF-CY items by age groups. In fact, participant responses from the first two rounds of online surveys produced four unique age based item sets that were approximately half of the initial items presented for each age group. Due to the high level of consensus on essential items in the first two rounds and with the relatively low sample attrition rate, the four age based derived code sets were presented for final participant review and endorsement in the third round survey. Endorsement rates for the proposed developmental code sets were high (87% to 95%), which suggests that the iterative process used in the study to achieve consensus from a diverse group of experts was an effective method that enabled the successful completion of the broad study goals. The Results chapter begins with an overview of response rate and sample retention. The next three sections present findings from each round of data collection. The summary of survey round three includes the final versions of the derived ICF-CY Developmental Code Sets. The chapter concludes with level of participant endorsement and comparisons of content and domain representation across the four code sets.

#### **Response Rates**

There were 151 individuals who participated in the study. Response rates for the study started at a high level (92%) and declined at subsequent rounds (79.5%, 71.5%, respectively). The final sample attrition was considerably lower than normal, where mean attrition rates were reported to be at 50% or higher between survey rounds (Finger et. al., 2006). Depending on the method used to determine response rates, the study had approximately 92% of the original consented sample survey complete at least one round of the survey and 69% of the original survey participants complete all three rounds of data collection. In the final round, 82% of participants who completed round two also completed round three of the survey. Response rates are presented in Table 1.

Table 1. *Response Rate*

	Consented	Responded	Opt out	No response	Response Rate
Round 1	164	151	4	9	92%
Round 2	161	128	2	31	79.5%
Round 3	158	113	-	45*	71.5%**

Note. \*(20 of these participants did not participate in round 2)

\*\* (81.8% of those who participated in round 2; 75% of those who participated in round 1)

Seventy five percent of the original sample who completed the initial round of surveys also completed the final survey which provided a review and endorsement of final developmental code set items. In addition, emails sent with the round one survey link were never accessed by five of the original participant list. A follow-up email was sent after the third round of the data collection to these five consented participants in an effort to obtain more understanding about the nature of the nonresponse. Because the emails had not bounced back as invalid addresses, a personal email asked the individuals to reply if the

emails had been received or were sent to the intended person. Only one of the five consented participants responded to this final follow-up message. This person indicated not having time to complete surveys due to a change in employment; however, the individual also reported remaining interested in the study and requested a copy of the final developmental code sets.

The five individuals who never accessed the emails containing the round one survey link were counted as passive refusals and included in the non-response column in Table 1. Two additional consented sample members indicated via email that they would not be able to participate during the initial round, and one person had difficulty accessing the survey via the link provided in their work email. Altogether less than eight percent of the original consented sample did not participate in the study and only four percent of the sample explicitly stated that they did want to participate after consenting to the official email invitation and subsequently receiving the first round survey.

Efforts to maintain sample participation involved email reminders between survey rounds to complete surveys by indicated deadlines, as well as individualized emails for each participant before the second and third data collection rounds. The individualized emails sent between rounds included two documents. Each participant received a summary of the combined participant ratings for each survey item from the previous round and a document that provided their personal responses for the same items for comparison before receiving the link to the next online survey. Individuals who did not complete the first or second survey during the data collection round and who had not explicitly declined further study participation were also sent the combined item level responses in an effort to facilitate future

participation. Findings from the online surveys are presented next. Data are presented for each round of the study starting with findings from the first survey. The results chapter ends with tables that display the four derived developmental code sets presented to the sample in round three and the subsequent participant ratings on the perceived quality and level of endorsement of these final item sets.

### **Summary of Survey One Results**

The first online survey collected background information about the study sample and participant ratings on the importance and developmental appropriateness of 142 second and third level codes from the ICF-CY Body Functions, Activities and Participation, and Environmental Factors domains for inclusion in age-based reduced item code sets. Information about sample characteristics is presented first and followed by analysis of participant ratings of individual ICF-CY items.

#### **Sample Characteristics**

Involving a professionally and culturally diverse sample was imperative given the study purpose and research design. Therefore a series of items in the first survey asked participants to share background information about their education, professional experience and discipline, nature of current work, and involvement in international research, policy, or practice to evaluate the extent to which intended diversity was achieved. Individuals recruited for the study were nominated to reflect the diversity inherent in a universal taxonomy designed for professionals trained in a range of disciplines, working in a variety of

settings, and residing in any country. Participants were also expected to have a similar high level of education and professional experience to qualify as knowledgeable and informed with regard to functional characteristics of child development. Indeed, general sample composition goals were met as the sample involved highly experienced and educated professionals from various professional disciplines and all major world regions. Responses to background questions from the first survey are summarized next according to the following dimensions: global representation of sample, nature of participant work, and professional experience and level of education.

**Global Representation.** Professionals from 27 different countries participated in the study (see Table 2). In addition, more than half of the sample was currently involved in work or had worked in at least one other country to contribute to international research, policy, program design or practice (n= 79, 52%). Participants indicated related work experience within 21 other countries. Thus, in total, study participants reported professional involvement in over 48 different countries indicating a sample with considerable experience working within a broad range of cultures. Specifically, participants indicated a current primary residence in the following countries arranged in descending order: United States of America, Canada, Portugal, South Africa, Finland, Australia, England, Sweden, China, Mexico, Israel, Taiwan, The Netherlands, Turkey, Denmark, Japan, New Zealand, Singapore, South Korea, Austria, Syria, Russia, Germany, India, Spain, Ethiopia, and Ukraine. Six of the participants indicated two primary countries for residency (China / Taiwan n=3, Sweden / Turkey n=1,



Russia / Ukraine n=1, South Korea/ United States n=1).

Table 2. *Sample Representation by Country*

<b>Primary Residency</b>	<b>N</b>	<b>Percentage (n=151)</b>
United States of America (USA)	64	42.3%
Canada	12	7.9%
Portugal	10	6.6%
South Africa	9	6.0%
Finland	6	4.0%
Australia	6	4.0%
England	5	3.3%
Sweden	5	3.3%
China	4	2.6%
Mexico	4	2.6%
Israel	4	2.6%
Taiwan	4	2.6%
The Netherlands	3	2.0%
Turkey	3	2.0%
Denmark	3	2.0%
Japan	2	1.3%
New Zealand	2	1.3%
Singapore	2	1.3%
South Korea	1	0.7%
Austria	1	0.7%
Syria	1	0.7%
Russia	1	0.7%
Germany	1	0.7%
India	1	0.7%
Spain	1	0.7%
Ethiopia	1	0.7%
Ukraine	1	0.7%

Participants were asked to report other countries and world areas where they have been involved in child related work (e.g., collaborative research, program development, teaching, or practice). Most of the countries represented as a participant's primary residence were also indicated as an area where other participants engaged in temporary, collaborative, or international work. Specifically, participants identified also working in the following

countries as a non-resident: Australia (n=4), Canada (n=2), England (n=3), Finland (n=1), Ethiopia (n=3), Germany (n=3), India (n=3), Israel (n=3), Japan (n=2), Mexico (n=1), the Netherlands (n=1), Portugal (n=5), South Africa (n=1), Spain (n=2), Singapore (n=2), South Korea (n=1), Sweden (n=5), Taiwan (n=2), and the United States (n=9).

Overall international representation of other world regions where participants have worked is presented in Table 3. Respondents were also asked to specify the countries where they worked if they indicated involvement in international work within a world region. In addition, study participants specified the following additional countries where they worked: Kenya (n=1), Italy (n=3), Greece (n=1), Honduras (n=1), Costa Rica (n=1), Guatemala (n=2), Belgium (n=2), France (n=3), Norway (n=1), Brazil (n=1), Malaysia (n=1), Thailand (n=1), Cambodia (n=2), United Kingdom (n=3), Hungary (n=1), Ecuador (n=1), Vietnam (n=1), Indonesia (n=2), Czech Republic (n=2), Poland (n=1), and Slovakia (n=1).

Table 3. *Participant Involvement with Work in Other World Regions*

Region	N	Percentage
Africa	13	8.6%
Asia-Pacific	21	13.9%
Central Asia	4	2.6%
Europe	34	22.5%
North America	30	19.9%
Middle East	5	3.3%
South America	3	1.9%
Southeast Asia	6	3.9%

**Education.** Ratings of ICF-CY items were intended to reflect the informed opinions of knowledgeable and respected professionals. Accordingly, study participants tended to be highly educated with several years of professional experience. All of the participants had at

least a four year college or university degree. Most of the participants had a graduate degree (89.9%). Forty-one percent of the sample had a masters or specialist degree and 49% had a PhD or MD.

**Professional Experience.** The majority of the sample reported working more than 10 years in their respective professional field (64%). Almost one-third of the sample indicated at least 20 years of professional work experience (31%). Less than seven percent of the sample had five years or less professional experience. Considering that the majority of the respondents were recruited as established experts with demonstrated knowledge, a substantial length of time working in their professional field was expected and desirable to enhance the credibility of the findings. These numbers are consistent with the study aim to recruit a diverse sample of experts knowledgeable about child development from different professional backgrounds, training, and settings.

**Professional Diversity.** At least 13 different professional disciplines were represented including psychology, medicine, speech and language pathology, physical therapy, occupational therapy, education, and special education (Table 4). Disciplines that appeared to be better represented in the sample include psychology, physical therapy, speech and language pathology, and occupational therapy. However, many participants indicated that the best description of their professional field fell under the category of researcher (21.4%) or professor (10.3%), which does not specify the particular discipline or field that the participant represents. Thus, clear representation of the distribution of professional disciplines for sample participants cannot be determined.

Table 4. *Category Rated to Best Describe Participant Professional Field*

Professional Field	N	Percentage
Researcher	31	21.4%
Psychologist	30	20.7%
Professor	15	10.3%
Physical Therapist	13	9.0%
Speech Language Pathologist	13	9.0%
Occupational Therapist	10	6.9%
Medical Doctor / Physician	9	6.2%
Child Development Specialist	9	6.2%
Special Education Teacher	5	3.4%
Social Worker	5	3.4%
Administrator	2	1.4%
Audiologist	1	0.07%
Early Childhood Educator	1	0.7%
Educator (elementary school)	1	0.7%
Nurse	1	0.7%

In addition, participants were asked to indicate the current nature of their work. Responses were not limited to one category. Responses suggest varied professional activities including clinical, academic, and clinical work. More than half of the sample reported involvement in research and almost half of the sample indicated teaching as a component of their current position (Table 5).

Table 5. *Current Nature of Participant Work*

	N	Percentage
Research	83	55.3%
Teaching	62	41.3%
Clinical	51	34.0%
Administration	31	20.7%
Other	17	11.3%
Graduate student	9	6.0%
Policy making	6	4.0%
Advocacy (parent/child)	5	3.3%

**Familiarity with ICF-CY.** Participants were asked to indicate familiarity with the ICF-CY and prior involvement with the ICF-CY before rating select items for the code sets. The reported level of familiarity with the ICF-CY varied. An equal number of participants indicated that they were not at all familiar with the ICF-CY and extremely familiar with the ICF-CY (i.e., 16.7% for both categories). Thirty-four percent of the sample reported being somewhat familiar with the ICF-CY, 20% reported being familiar, and 12.7% of the sample indicated that they were very familiar. Regarding prior involvement with the ICF-CY, 60.9% of the sample indicated no experience using the ICF-CY in research, practice, or for program or policy development. However more than a third of the sample (37%) reported experience using the ICF-CY and 13% of the sample reported involvement in the development of the ICF-CY.

### **Comparison of Sample Characteristics by Primary Residency**

The most represented country for primary residency in the sample was the United States. As the findings are intended to represent consensus from an international sample, a comparison of ratings for non-US participants (n=87) and US participants (n=64) for survey one was conducted. Analysis performed to examine differences in background characteristics for study participants revealed similar education level and years of experience for US and non-US participants.

**Work Experience and Education.** The nature of work for US and non-US participants was examined across types of professional responsibilities. Participants who were residents of the United States reported that they were involved in research (42.9%), clinical practice (36.5%), teaching (30.2%), administrative work (15.9%), graduate school

(7.9%), policy (4.8%), advocacy (4.8%). Almost 40% of the US sample reported working in their respective fields more than 15 years with 32.8% indicating over 20 years of work experience. Only 26% of the US participants reported five years or less professional experience. Regarding education, the vast majority of the US sample had a graduate degree (93.8%) and more than half reported that they had a MD or PhD (54.7%). In addition, many of the US participants indicated involvement in work outside of the US (42%).

For the non-US sample, more participants indicated involvement in research, teaching, and administrative work as part of their current job. Specifically, 64% of non-US Sample engage in research compared to 43% of the US sample. Almost half of the non-US participants teach (49.4%) and 24% engaged in administrative work. The distribution of clinical practice, involvement in policy and advocacy work was similar (i.e., 32.2% perform clinical work for non-US sample compared to 36%; 3.4% are involved in policy, and 2.3% advocacy). Participants from a country other than the United States also had extensive experience in their respective field (i.e., 43% of non-US sample have been involved in their profession for over 15 years with 29.9% reporting over 20 years). Similar to the US sample, the majority of participants had a graduate degree (87.1%) and almost 60% indicated involvement in work outside of their own country or working in other regions of the world.

**ICF-CY Familiarity.** In general, participants outside of the US reported more familiarity and experience with the ICF-CY compared to participants from the US. Approximately 11% of the US sample rated that they were very familiar or extremely familiar with the ICF-CY at the start of the study and almost 29% of the US sample indicated they were not at all familiar with the ICF-CY. Only eight percent of the non-US sample

indicated that they were not at all familiar with the ICF-CY and over 42% reported being very familiar or extremely familiar. Regarding ICF-CY application, 84% of the US sample reported that they have never used the ICF-CY in research, practice, or for program or policy development while more than half of the non-US sample indicated prior use (55.2%). In addition, only one respondent from the US was involved in ICF-CY development but 19 participants from non-US country reported involvement in the development or review of the ICF-CY.

### **ICF-CY Item Ratings for Survey One**

Participants were asked to indicate ICF-CY items they thought were essential to consider for the reduced item developmental code sets. The first round survey had 142 items/codes from the ICF-CY. Participants were asked to consider all 142 items for each of the four age groups and indicate if the item was appropriate and essential to include in the code sets. The items were separated by domain and organized according to the structure and categories of the ICF-CY. The percentage of items endorsed varied across the four age ranges, as did the actual items such that none of the original ICF-CY items were endorsed for all four age groups. Items marked by at least 75% of the sample were retained for the second round. At least 35% of items were not indicated in each group, and these varied across groups suggesting differences by developmental expectation rather than less important codes for children and youth in general.

Participants endorsed the greatest number of ICF-CY items as appropriate and essential for the 6-12 year development code set (64% of items) and the least number for the under age 3 group (31.7%). Approximately half of the items were rated as essential for the 3-5 year and 13-17 year developmental item sets. The numbers of items rated across each domain for each age group the original items are presented in Table 6. Items not endorsed at the set limit were dropped for the second round survey.

*Table 6. Number of Items Rated as Essential in Round One by Age Group*

	Activities and Participation	Body Functions	Environment	Total Items	% Retained
0-2	13	24	8	45	31.7%
3-5	22	31	18	71	50.0%
6-12	37	26	29	92	64.8%
13-17	26	21	28	72	50.7%

Original ICF-CY items were endorsed as appropriate and essential to include in the final developmental code sets for all three ICF-CY domains. The 142 items were not evenly split across domains in the first survey (i.e., 63 codes for Activities and Participation, 50 for Body Functions, and 29 codes for Environmental Factors). A comparison of items that were endorsed in each domain across all four age groups revealed the highest retention for Body Functions items. The percentage of Body Functions codes endorsed by proposed set ranged from 42% for the 13-17 age group to 62% for the 3-5 age group with approximately half retained for the 0-2 and 6-12 age groups. The amount of Activities and Participation codes endorsed ranged from 20% (0-2 age group) to approximately 59% (6-12 age group). Finally, the most variability was found for Environmental Factors codes with approximately 28%



endorsed for the 0-2 set, 62% for the 3-5 set, 97% for the 13-17 set, and full endorsement at 100% for the 6-12 set.

### **Summary of Survey Two Results**

In the second round of data collection participants were asked to review retained items and rate each by level of importance for inclusion for specific developmental code sets. Participants were now asked to consider and evaluate the relative importance of items to be included as part of the ICF-CY universal minimal item sets for reference in research, policy or clinical applications with children. Only items that were endorsed in the first survey by at least 75% of study participants were included in the second round online survey.

Codes were arranged by age group for the second questionnaire, rather than by ICF-CY domain as endorsed items varied by group. Items were rated on a three-point scale (i.e., essential, very important, or somewhat important to include). Because items were already determined to be important by the majority of the sample, response categories did not include an option to indicate that an item was not important. However, participants were able to provide feedback, suggest missed areas or items, and make general comment in an open-ended question for each age group.

Participants were able to rank the relative importance of survey two items and designate select items as essential to include in the final developmental code sets for the four age ranges. Ratings of items were examined for percent agreement at the essential level as well as the combined essential and very important agreement levels.

While all items endorsed by the majority of participants as essential to include were retained for the third round (i.e., over 50% endorsement), items that did not meet this criteria also tended to be rated by more of the sample as somewhat important rather than very important. The total number of items that were retained after the second round data analysis consensus process is presented in Table 7. Table 7 also includes the number of possible items that could have been endorsed in the second survey and the rates of retention after the two data collection rounds. The majority of second survey items were indicated as essential to include in the final developmental code sets with 65% to 82% of items endorsed.

*Table 7. Comparison of Items Retained After the First and Second Data Collection Rounds*

	Activities & Participation	Body Functions	Environment	Total items
0-2	13 / 13 (100%)	16 / 24 (66.7%)	8 / 8 (100%)	37 / 45 (82.2%)
3-5	18 / 22 (81.8%)	16 / 31 (51.6%)	18/18 (100%)	52 / 71 (73.2%)
6-12	27 / 27 (100%)	20 / 26 (76.9%)	13 / 29 (44.8%)	60/92 (65.2%)
13-17	23 / 26 (88.5%)	16 / 21 (76.2%)	19/28 (67.9%)	58/72 (80.5%)

### **Summary of Survey Three Results**

A high level of agreement among study participants was reached regarding items essential to include in the developmental code sets after the first and second data collection rounds. Less than half of the original 142 ICF-CY codes rated by participants met consensus criteria for inclusion in the third survey. The percent of original items retained ranged from 26% to 42% across the different age sets. Given the sample consensus and overall reduction in the number of initial ICF-CY codes, the third survey presented items as potential final versions of the ICF-CY Developmental Code Sets. Because the number of items that could

be rated as very important or critical to include was not limited in prior data collection rounds, there was variability in the total number of items retained across the four age groups. The 6-12 age range retained the most items from the original survey (42.3%) while the 0- 2 age set had the least amount (26.1%).

Table 8. *Final Number of Items in the Developmental Code Sets & Percentage Retained*

	Activities and participation=63	Body Functions=50	Environmental Factors=29	Total items=142
0-2	13 (20.6%)	16 (32.0%)	8 (27.6%)	37 (26.1%)
3-5	18 (28.6%)	16 (32.0%)	18 (62.1%)	52 (36.6%)
6-12	27 (42.9%)	20 (40.0%)	13 (44.8%)	60 (42.3%)
13-17	23 (36.5%)	16 (32.0%)	19 (65.5%)	58 (40.8%)

## Final Developmental Code Sets

The developmental code sets are presented in Tables 9-12. These items are arranged under the ICF-CY domains.

Table 9. *ICF-CY Developmental Code Set for Children Birth to 35 months (0-2)*

<b>ACTIVITY AND PARTICIPATION</b>
Exploring objects by mouthing, touching, tasting or smelling
Watching and Listening to engage in purposeful sensory experiences (i.e., intentionally experiencing auditory and visual stimuli)
Learning through actions with objects (e.g., manipulate, bang, mouth or put a lid on a box)
Learning through play and playing with objects, (e.g., stir with a spoon, pretend that a piece of wood is a car)
Comprehending meaning of messages in spoken language, receiving and understanding verbal communication [Communication]
Vocalizing when aware of another person in the proximal environment (e.g., babbling and producing other sounds in turn-taking activities)
Changing basic body position (e.g. turn in bed, sit up, stand) [Mobility]
Maintaining a body position (e.g., control head position, remain seated at school or stand in play)
Using hands and arms (e.g., grasp and pick up objects, grasp raisins, button shirt, throw or catching a ball)
Moving around (e.g., crawl, scoot, climb stairs, run and jump)
Differentiation of familiar persons [Interpersonal Interactions and Relationships]
Playing (e.g., engage with objects, toys, or others, occupy oneself in playful activity, alone or with another)

Wakefulness, alertness, and awareness of the child or youth
<b>BODY FUNCTION</b>
Seeing functions (e.g., sense the presence of light; sense the form, size, shape and color of the visual stimuli)
Hearing functions (e.g., sense the presence of sounds and discriminate the location, pitch, loudness and quality of sounds)
Touch functions (sense qualities of bitterness, sweetness, sourness, and saltiness)
Sensation of pain (e.g., the child reacts when falling, indicates pain in body part or generally)
Emotions regulation and range of emotion (e.g. appropriateness of emotions like affect, sadness, happiness, fear, anger, frustration)
Voice and producing sounds and speech (production and quality of voice, phonation, pitch, loudness)
Heart functions (e.g., heart rate, heart rhythm, functions of heart valves, blood pressure, circulation)
Respiration functions (e.g., respiration rate, respiratory rhythm, depth of respiration)
Immune response (i.e., resistance to infections)
Eating and drinking functions (e.g. chewing, sucking, biting, manipulation of food in the mouth, salivation, swallowing)
Breakdown of food and tolerance to food (e.g., transport of food through stomach and intestines, breakdown of food, absorption of nutrients, functions of accepting suitable food and drink for digestion)
Growth maintenance functions (attain expected physical milestones)
Motor reflexes (i.e. involuntary contraction of muscles automatically induced by specific stimuli, infant reflexes)
Muscle tone (i.e., tension present in resting muscles and the resistance offered when trying to move the muscles passively. It can appear like hypotonia, hypertonia, spasticity)
Spontaneous movements. This is about the infants movements and changes of body positions.
Postural, balance or threatening reactions (supporting, self-protecting and defensive reactions)
<b>ENVIRONMENTAL FACTORS</b>
Food and drink (e.g., appropriateness, nutrition, amount, consistency)
Drugs (type of drug and amount for medical purposes)
Products and technology used for play (e.g., household objects, toys, other products like balls, games, puzzles, or adapted material for play. Indoor and playground)
Immediate family
Health Professionals
Individual attitudes of immediate family members
Social support services, systems, policies (public assistance other than social security)
Health services (e.g. access to early intervention, technical aids, other health services)

Table 10. *ICF-CY Developmental Code Set for Children 3-5 Years Old*

<b>ACTIVITIES AND PARTICIPATION</b>
Learning through play and playing with objects, (e.g. stir with a spoon pretend that a piece of wood is a car)
Developing competency using words, phrases or sentences to represent persons, objects, events etc
Acquiring basic concepts like size, form, quantity, length, same, opposite
Undertaking a single task or responding to a single communication (e.g., put on a sock, do homework, sort objects, play hide and seek, take instruction)
Comprehending meaning of messages in spoken language, receiving and understanding verbal communication
Comprehending meanings of nonverbal messages in body gestures, general signs and symbols, drawings and photographs

Speaking and telling someone something (i.e., produce verbal communication)  
 Using gestures, symbols and drawings to communicate (i.e., producing nonverbal messages)  
 Having a conversation (i.e., initiate, maintain, shape or terminate communicative interactions)  
 Using hands and arms (e.g., grasp and pick up objects, grasp raisins, button shirt, throw or catching a ball)  
 Walking indoors or outdoors  
 Moving around (e.g., crawl, scoot, climb stairs, run and jump)  
 Moving around using equipment (e.g., use wheel chair, walker, or ski to move around)  
 Toileting (i.e., regulating urination and defecation)  
 Eating and drinking (i.e., indicate need for and coordinate tasks and actions of eating food and drinking)  
 Interacting with people (i.e., basic interpersonal interactions including respond to other's feelings, show respect in relationships, use appropriate physical contact)  
 Engaging in preschool education (e.g. acquire skills, follow teacher's instructions)  
 Playing (e.g., engage with objects, toys, or others, occupy oneself in playful activity, alone or with another)

### **BODY FUNCTIONS**

Sleep functions (e.g., amount of sleeping and onset, maintenance and quality of sleep)  
 Attention functions (e.g. sustain, shift, divide and share attention; concentration)  
 Memory functions (e.g., to remember, learn and recall things)  
 Perceptual functions (e.g., recognize and interpret sensory stimuli like auditory, visual, tactile, gustatory or olfactory stimuli)  
 Sensation of pain (e.g. the child reacts when falling, indicates pain in body part or generally)  
 Voice and producing sounds and speech (production and quality of voice, phonation, pitch, loudness)  
 Heart functions (e.g., heart rate, heart rhythm, functions of heart valves, blood pressure, circulation)  
 Immune response (i.e. resistance to infections)  
 Respiration functions (e.g., respiration rate, respiratory rhythm, depth of respiration)  
 Eating and drinking functions (e.g. chewing, sucking, biting, manipulation of food in the mouth, salivation, swallowing)  
 Defecation (e.g., frequency, air or gases from the intestines, fecal consistency, voluntary control over elimination)  
 Growth maintenance functions (attain expected physical milestones)  
 Urination (e.g., frequency, urine retention, control over urination)  
 Muscle tone (i.e. tension present in resting muscles and the resistance offered when trying to move the muscles passively. It can appear like hypotonia, hypertonia, spasticity.  
 Postural, balance or threatening reactions (e.g., supporting, self-protecting and defensive reactions)  
 Voluntary movement, (i.e. control and coordination). It can appear like clumsiness, dysdiadochokinesia

### **ENVIRONMENTAL FACTORS**

Food and drink (e.g., appropriateness, nutrition, amount, consistency)  
 Drugs (type of drug and amount for medical purposes)  
 Products and technology for personal use in daily living (e.g., furniture, stroller, chairs, personal care equipment, adapted or specially designed devices, and orthopedic devices)  
 Products and technology for personal indoor and outdoor mobility and transportation (e.g., family car, cab. Bus, train, adapted chairs, walking devices, wheelchair, bicycle)  
 Products and technology for communication (e.g., telephone, TV and video, computers/ email, glasses and aids for sight and hearing, aids for writing)  
 Products and Technology for education (e.g., books, computers, educational toys, adapted material for learning such as computer software)

Products and technology for culture, recreation, and sport (e.g., skis, musical instruments, adapted equipment)

Products and technology used for play (e.g., household objects, toys, other products like balls, games, puzzles, or adapted materials for play; indoor and playground)

Immediate family

Extended family

Friends

Personal care providers and personal assistants

Health professionals

Individual attitudes of immediate family

Individual attitudes of extended family

Individual attitudes of health professionals

Design, construction, and building products and technology of buildings for private use (e.g., thresholds, ramps, doorknobs, toilets, lighting, contrasts in color, kitchen interior).

Social support services, systems, policies (public assistance other than social security)

Table 11. *ICF-CY Developmental Code Set for Children 6-12 Years Old*

<b>ACTIVITIES AND PARTICIPATION</b>
Learning to read
Learning to write
Learning to calculate
Focusing attention on specific stimuli without being disturbed by sounds
Reading (i.e. comprehension, to understand a text and read aloud or in silence to gain information)
Writing (i.e. to convey information and formulate written text understanding spelling, grammar)
Calculating (i.e. perform computations and apply mathematical principals)
Solving problems (i.e. find solutions to questions or situations)
Making decisions or choosing between different alternatives (e.g. different kinds of food, plays, leisure activities)
Directing attention (e.g., focusing on specific action, task)
Thinking (e.g., form ideas, reflect, consider, analyze information)
Undertaking multiple tasks or responding to a command with multiple components or sequence (e.g., dress, make dinner or take a number of instructions)
Carrying out daily routines (e.g., get up in the morning, get ready for school, manage time)
Handling stress and other psychological demands (e.g., take exams, move around in heavy traffic, wait for ones turn, cope with difficulties)
Managing one's own behavior (e.g., adapt and respond to novel situations, manage emotional expression)
Comprehending meanings of nonverbal messages in body gestures, general signs and symbols, drawings and photographs
Having a conversation (i.e., initiate, maintain, shape or terminate communicative interactions)
Caring for the body (e.g., brush teeth, comb ones hair, shave)
Washing and drying the body (e.g., bathing, wash hands)
Dressing oneself including choosing appropriate clothes for a situation
Avoiding dangerous situations and harm to self
Interacting with people (i.e., basic interpersonal interactions including respond to other's feelings, show respect in relationships, use appropriate physical contact)
Creating and maintaining family relationships
Forming, maintaining and managing interactions with others in a contextually and socially appropriate manner

Engaging in school education (e.g., work with other students, follow teacher's instructions, learn material, do homework)
Engaging in recreational or leisure activity (e.g., informal or organized play and sports, museums, cinemas, crafts, hobbies, playing musical instruments)
Playing (e.g., engage with objects, toys, or others, occupy oneself in playful activity, alone or with another)
<b>BODY FUNCTIONS</b>
Basic mental functions (e.g., to know and reason, carry out tasks demanding understanding of how situations work out)
Temperament and personality functions (e.g., extraversion, agreeableness, psychic stability)
Energy and drive functions (e.g., mental functions to produce vigor, stamina, motivation, regulate impulses, and/or natural longing or desire for food and drink)
Sleep functions (e.g., amount of sleeping and onset, maintenance and quality of sleep)
Attention functions (e.g. sustain, shift, divide and share attention; concentration)
Memory functions (e.g., to remember, learn and recall things)
Psychomotor control (e.g. manual and lateral dominance, posturing, quality of psychomotor function, regulation of speed concerning movements or speech)
Emotions regulation and range of emotion (e.g. appropriateness of emotions like affect, sadness, happiness, love, fear, anger, tension, hate)
Thought functions (e.g., to control pace, form and content of thought, goal directed and logical thoughts, coherence of thought)
Specific mental functions (e.g. abstract thinking, to plan and carry out plans, decision-making)
Mental functions of language (e.g., to recognize and use spoken, written or other forms of language like signs, pictures, pictogram etc)
Articulation
Fluency (e.g., fluency, rhythm of speech etc.)
Heart functions (e.g., heart rate, heart rhythm, functions of heart valves, blood pressure, circulation)
Immune response (i.e., resistance to infections)
Respiration functions (e.g., respiration rate, respiratory rhythm, depth of respiration)
Weight maintenance (e.g., appropriate Body Mass Index including weight gain)
Growth maintenance functions (attain expected physical milestones)
Muscle tone (i.e., tension present in resting muscles and the resistance offered when trying to move the muscles passively. It can appear like hypotonia, hypertonia, spasticity)
Voluntary movement, (i.e., control and coordination) it can appear like clumsiness, dysdiadochokinesia)
<b>ENVIRONMENTAL FACTORS</b>
Immediate family
Food and drink (e.g., appropriateness, nutrition, amount, consistency)
Drugs (type of drug and amount for medical purposes)
Products and technology for use in daily living (e.g., furniture, stroller, chairs, personal care equipment, adapted or specially designed devices, and orthopedic devices)
Products and technology for communication (e.g., telephone, TV and video, computers/ email, glasses and aids for sight and hearing, aids for writing)
Products and Technology for education (e.g., books, computes, educational toys, adapted material for learning such as computer software)
Friends
Individual attitudes of immediate family members
Individual attitudes of friends
Design, construction, and building products and technology of buildings for private use (e.g.,

thresholds, ramps, doorknobs, toilets, lighting, contrasts in color, kitchen interior).  
 Design, construction and building products and technology of buildings for public use (e.g.,  
 entrees, elevators, door openers, signs, hearing devices, picture support, Braille, security  
 equipment)  
 Social support services, systems, policies (public assistance other than social security)  
 Health services (e.g., access to early intervention, technical aids, other health services)

Table 12. *ICF-CY Developmental Code Set for Children 13-17 Years Old*

<b>ACTIVITIES AND PARTICIPATION</b>
Reading (i.e. comprehension, to understand a text and read aloud or in silence to gain information)
Writing (i.e. to convey information and formulate written text understanding spelling, grammar)
Calculating (i.e. perform computations and apply mathematical principals)
Solving problems (i.e. find solutions to questions or situations)
Making decisions or choosing between different alternatives (e.g. different kinds of food, plays, leisure activities)
Thinking (e.g., form ideas, reflect, consider, analyze information)
Handling stress and other psychological demands (e.g., take exams, move around in heavy traffic, wait for ones turn, cope with difficulties)
Managing one's own behavior (e.g., adapt and respond to novel situations, manage emotional expression)
Having a conversation (i.e., initiate, maintain, shape or terminate communicative interactions)
Using telephone or email
Using transportation (e.g., ride a bicycle or a moped, drive a car)
Caring for the body (e.g., brush teeth, comb ones hair, shave)
Preparing meals, helping to make meals (e.g. take out ingredients, cook, set the table)
Doing housework (e.g., do laundry or clean room)
Looking after one's health (e.g., keep warm or cool, diet and fitness)
Avoiding dangerous situations and harm to self
Assisting others (e.g., help siblings, be aware of family members' feelings and well-being)
Interacting with people (i.e., basic interpersonal interactions including respond to other's feelings, show respect in relationships, use appropriate physical contact)
Creating and maintaining family relationships
Creating and maintaining intimate relationships
Forming, maintaining and managing interactions with others in a contextually and socially appropriate manner
Engaging in simple economic transactions (e.g., use money to purchase food, exchange goods or services, save money)
Engaging in recreational or leisure activity (e.g., informal or organized play and sports, museums, cinemas, crafts, hobbies, playing musical instruments)
<b>BODY FUNCTIONS</b>
Temperament and personality functions (e.g., extraversion, agreeableness, psychic stability)
Energy and drive functions (e.g., mental functions to produce vigor, stamina, motivation, regulate impulses, and/or natural longing or desire for food and drink)
Sleep functions (e.g., amount of sleeping and onset, maintenance and quality of sleep)
Attention functions (e.g. sustain, shift, divide and share attention; concentration)
Memory functions (e.g., to remember, learn and recall things)
Emotions regulation and range of emotion (e.g. appropriateness of emotions like affect, sadness, happiness, love, fear, anger, tension, hate)



Thought functions (e.g., to control pace, form and content of thought, goal directed and logical thoughts, coherence of thought)  
 Specific mental functions (e.g. abstract thinking, to plan and carry out plans, decision-making)  
 Mental functions of language (e.g., to recognize and use spoken, written or other forms of language like signs, pictures, pictogram etc)  
 Heart functions (e.g., heart rate, heart rhythm, functions of heart valves, blood pressure, circulation)  
 Immune response (i.e., resistance to infections)  
 Respiration functions (e.g., respiration rate, respiratory rhythm, depth of respiration)  
 Sensations associated with cardiovascular and respiratory functions (e.g., sensations of tightness of chest, feelings of irregular beat, choking, gagging and wheezing)  
 Weight maintenance (e.g., appropriate Body Mass Index including weight gain)  
 Growth maintenance functions (attain expected physical milestones)  
 Menstruation functions

### **ENVIRONMENTAL FACTORS**

Food and drink (e.g., appropriateness, nutrition, amount, consistency)  
 Drugs (type of drug and amount for medical purposes)  
 Products and technology for personal use in daily living (e.g., furniture, stroller, chairs, personal care equipment, adapted or specially designed devices, and orthopedic devices)  
 Products and technology for personal indoor and outdoor mobility and transportation (e.g., family car, cab. Bus, train, adapted chairs, walking devices, wheelchair, bicycle)  
 Products and technology for communication (e.g., telephone, TV and video, computers/ email, glasses and aids for sight and hearing, aids for writing)  
 Products and Technology for education (e.g., books, computers, educational toys, adapted material for learning such as computer software)  
 Products and technology for culture, recreation, and sport (e.g., skis, musical instruments, adapted equipment)  
 Immediate family  
 Friends  
 People in a position of authority  
 Personal care providers and personal assistants  
 Acquaintances, peers, colleagues, neighbors, and community members  
 Individual attitudes of immediate family members  
 Individual attitudes of friends  
 Design, construction, and building products and technology of buildings for public use (e.g., entrances, elevators, door openers, signs, hearing devices, picture support, Braille, security equipment).  
 Design, construction and building products and technology of buildings for public use (e.g., entrances, elevators, door openers, signs, hearing devices, picture support, Braille, security equipment)  
 Transportation (services aimed at moving persons or goods by road, path, rail, air or water, by public or private transport)  
 Social support services, systems, policies (public assistance other than social security)  
 Health services (e.g. access to early intervention, technical aids, other health services)

## Distribution of codes by ICF-CY Domain

The number of items retained within the Activities and Participation, Body Functions and Environmental Factors domains was examined relative to the total number of final items in each code set. Consistent with ratings in the first survey, there was variability in the distribution of items by domain across the four code sets, although each code set had representation in each area. Relative domain representation varied from 21% to 43%. Item distribution by ICF-CY domain for each developmental code set is presented in Table 13. For the 0-2 code set, approximately 43% of the final items were from the Body Function domain and 22% of the items were from the Environment domain. The number of final items for the 3-5 code set was generally equal across the three domains (i.e., with 31% to 35% representation). The 6-12 code set is comprised of the most number of items, and 45% of these items fall under the Activities and Participation domain.

Table 13. *Relative Representation of ICF-CY Domains by Age Set*

	Activities & Participation	Body Functions	Environment	Total items
0-2	13 (35.1%)	16 (43.2%)	8 (21.6%)	37
3-5	18 (34.6%)	16 (30.8%)	18 (34.6%)	52
6-12	27 (45.0%)	20 (33.3%)	13 (21.7%)	60
13-17	23 (39.7%)	16 (27.6%)	19 (32.8%)	58

## Items Shared Across Developmental Code Sets

**Activities & Participation Items.** None of the original ICF-CY codes were included in all four developmental code sets under the Activities and Participation domain. However, there were three codes that were shared across three different age ranges and 17 additional codes endorsed across two of the final developmental code sets (Table 14). Specifically, the following three codes that were rated as essential across three codes sets: interacting with

people (i.e., basic interpersonal interactions including respond to other’s feelings, show respect in relationships, use appropriate physical contact), playing (e.g., engage with objects, toys, or others, occupy oneself in playful activity, alone or with another), and having a conversation (i.e., initiate, maintain, shape or terminate communicative interactions). Items shared by only two code sets were either on the 0-2 and 3-5 years code sets or the 6-12 and 13-17 code sets. Six items that were rated as essential for children 6-17 years involved learning and applying knowledge (e.g., reading, writing, calculating). Not surprising, no items were shared between the youngest and oldest groups.

Along with specific items that were shared across two or more code sets, items in the Activities and Participation domain became increasingly complex at each higher age group. Supporting the validity of the ratings and Delphi process, the final developmental code sets included items that always progressed from simple to more complex. For example, “learning to read” at the 3-5 age group became the more advanced “Reading” ICF-CY code at 6-12; “Voice and producing sounds and speech (production and quality of voice, phonation, pitch, loudness)” at under 3 years was followed by “speaking and telling someone something (i.e., produce verbal communication)” and “having a conversation (i.e., initiate, maintain, shape or terminate communicative interactions)”.

*Table 14. Activity and Participation Items Shared Across Code Sets*

<i>Code Set &lt;3</i>	<i>Code Set 3-5</i>	<i>Code Set 6-12</i>	<i>Code Set 13-17</i>
<i>Learning and Applying Knowledge</i>			
131 Learning through play and playing with objects		163 Thinking 166 Reading 170 Writing 172 Calculating 175 Solving problems 177 Making decisions or choosing between different alternatives	
<i>General Tasks and Demands</i>			

	240 Handling stress and other psychological demands
	250 Managing one's own behavior
<i>Communication</i>	
310 Comprehending meaning of messages in spoken language, receiving and understanding verbal communication	
<b>350 Having a conversation</b>	
<i>Mobility</i>	
440 Using hands and arms	
455 Moving around	
<i>Self Care</i>	
	520 Caring for the body
	571 Avoiding dangerous situations and harm to self
<i>Interpersonal Interactions and Relationships</i>	
<b>710 Interacting with people</b>	
	760 Creating and maintaining family relationships
	720 Forming, maintaining and managing interactions with others in a contextually and socially appropriate manner
<i>Major Life Areas</i>	
<b>880 Playing</b>	
<i>Community, Social and Civic Life</i>	
	920 Engaging in recreational or leisure activity

**Body Functions Domain.** Several items from the Body Function domain of the ICF-CY were rated as essential for two or more Developmental Code Sets. The following four original (survey one) items were included in all final code sets: heart functions, immune response, respiration functions, and Growth maintenance functions (attain expected physical milestones). Five items were rated as essential for three of the four developmental code sets, and 11 additional items are included in two of the code sets. These items are displayed in Table 15.

Table 15. *Shared Items in Body Functions*

BODY FUNCTION	0-2	3-5	6-12	13-17
Basic mental functions (e.g., to know and reason, carry out tasks demanding understanding of how situations work out)			X	
Wakefulness, alertness, and awareness of the child or youth	X			
Temperament and personality functions (e.g., extraversion, agreeableness, psychic stability)			X	X
Energy and drive functions (e.g., mental functions to produce vigor, stamina, motivation, regulate impulses, and/or natural longing or desire for food and drink)			X	X
Sleep functions (e.g., amount of sleeping and onset, maintenance and quality of sleep)		X	X	X
Attention functions (e.g. sustain, shift, divide and share attention; concentration)		X	X	X
Memory functions (e.g., to remember, learn and recall things)		X	X	X
Psychomotor control(e.g. manual and lateral dominance, posturing, quality of psychomotor function, regulation of speed concerning movements or speech)			X	
Emotions regulation and range of emotion (e.g. appropriateness of emotions like affect, sadness, happiness, love, fear, anger, tension, hate)	X		X	X
Perceptual functions (e.g., recognize and interpret sensory stimuli like auditory, visual, tactile, gustatory or olfactory stimuli)		X		
Thought functions (e.g., to control pace, form and content of thought, goal directed and logical thoughts, coherence of thought)			X	X
Specific mental functions (e.g. abstract thinking, to plan and carry out plans, decision-making)			X	X
Mental functions of language (e.g., to recognize and use spoken, written or other forms of language like signs, pictures, pictogram etc)			X	X
Seeing functions (e.g., sense the presence of light; sense the form, size, shape and color of the visual stimuli)	X			
Hearing functions (e.g., sense the presence of sounds and discriminate the location, pitch, loudness and quality of sounds)	X			
Touch functions (sense qualities of bitterness, sweetness, sourness, and saltiness)	X			
Sensation of pain (e.g., the child reacts when falling, indicates pain in body part or generally)	X	X		
Voice and producing sounds and speech (production and	X	X		

quality of voice, phonation, pitch, loudness)				
Articulation			X	
Fluency (e.g., fluency, rhythm of speech etc.)			X	
Heart functions (e.g., heart rate, heart rhythm, functions of heart valves, blood pressure, circulation)	X	X	X	X
Immune response (i.e., resistance to infections)	X	X	X	X
Respiration functions (e.g., respiration rate, respiratory rhythm, depth of respiration)	X	X	X	X
Sensations associated with cardiovascular and respiratory functions (e.g., sensations of tightness of chest, feelings of irregular beat, choking, gagging and wheezing)				X
Weight maintenance (e.g., appropriate Body Mass Index including weight gain)			X	X
Eating and drinking functions (e.g. chewing, sucking, biting, manipulation of food in the mouth, salivation, swallowing)	X	X		
Breakdown of food and tolerance to food (e.g., transport of food through stomach and intestines, breakdown of food, absorption of nutrients, functions of accepting suitable food and drink for digestion)	X			
Defecation (e.g., frequency, air or gases from the intestines, fecal consistency, voluntary control over elimination)		X		
Growth maintenance functions (attain expected physical milestones)	X	X	X	X
Urination (e.g., frequency, urine retention, control over urination)		X		
Menstruation functions				X
Muscle tone (i.e., tension present in resting muscles and the resistance offered when trying to move the muscles passively. It can appear like hypotonia, hypertonia, spasticity)	X	X	X	
Motor reflexes (i.e. involuntary contraction of muscles automatically induced by specific stimuli, infant reflexes)	X			
Postural, balance or threatening reactions (supporting, self-protecting and defensive reactions)	X	X		
Spontaneous movements. (This is about the infant's movements and changes of body positions)	X			
Voluntary movement, (i.e., control and coordination) it can appear like clumsiness, dysdiadochokinesia)		X	X	

**Environmental Factors domain.** A comparison of Environmental Factors items revealed items that were rated as essential across all four developmental code sets (Table 16).

Specifically, food and drink, drugs, immediate family, attitudes of immediate family members, and social support services were identified as essential for children of all ages. Six additional items were rated as essential for three of the four code sets. Products and technology resources were generally viewed as essential for children over three years of age. Relationship items were rated most often in the 3-5 age set and 13-17 age set. Only immediate family was rated as an essential interpersonal relationship for children younger than three years of age.

Table 16. *Comparison of Environmental Factor Items by Code Set*

ENVIRONMENT	>3	3-5	6-12	13-17
Food and drink (e.g., appropriateness, nutrition, amount, consistency)	X	X	X	X
Drugs (type of drug and amount for medical purposes)	X	X	X	X
Products and technology for personal use in daily living (e.g., furniture, stroller, chairs, personal care equipment, adapted or specially designed devices, and orthopedic devices)		X	X	X
Products and technology for personal indoor and outdoor mobility and transportation (e.g., family car, cab, bus, train, adapted chairs, walking devices, wheelchair, bicycle)		X		X
Products and technology for communication (e.g., telephone, TV and video, computers/ email, glasses and aids for sight and hearing, aids for writing)		X	X	X
Products and Technology for education (e.g., books, computers, educational toys, adapted material for learning such as computer software)		X	X	X
Products and technology for culture, recreation, and sport (e.g., skis, musical instruments, adapted equipment)		X		X
Products and technology used for play (e.g., household objects, toys, other products like balls, games, puzzles, or adapted materials for play; indoor and playground)	X	X		
Immediate family	X	X	X	X
Extended family		X		
Friends		X	X	X
Personal care providers and personal assistants		X		X
People in a position of authority				X
Acquaintances, peers, colleagues, neighbors, and community members				X
Health professionals	X	X		
Individual attitudes of immediate family	X	X	X	X
Individual attitudes of extended family		X		
Individual attitudes of health professionals		X		
Individual attitudes of friends			X	
Design, construction, and building products and technology of		X	X	X

buildings for private use (e.g., thresholds, ramps, doorknobs, toilets, lighting, contrasts in color, kitchen interior).				
Social support services, systems, policies (public assistance other than social security)	X	X	X	X
Transportation (services aimed at moving persons or goods by road, path, path, rail, air, or water by public or private transport)				X
Health Services	X		X	X

### Endorsement of Final Developmental Code Sets

Participants were asked to rate how well they thought that the derived developmental code sets represent minimum critical areas of health, functioning or development for children in the four age groups and how well does each set represent critical, shared areas that can be used to document assets or problems for all children regardless of health condition or disability diagnosis. Ratings are displayed in Table 17. Although the birth through two years item set had the least amount of codes, it received the highest rating with the majority of the sample indicating an “excellent” representation score. In fact, all codes were rated as excellent or good by almost all of the participants (94.5%, 91.8%, 95.4%, and 89%, in order of age set). Few respondents rated the items adequate or somewhat representative; none rated the items as not at all representative.

*Table 17. Rating of Code Set Items to Represent Critical Functional Areas by age Group*

	Excellent	Good	Adequate	Somewhat	Not at all	I don't know
0-2 Code Set	60.6% (66)	33.9% (37)	3.7% (4)	0.0%	0.0%	1.8% (2)
3-5 Code Set	57.4% (62)	38.0% (41)	2.8% (3)	0.0%	0.0%	1.9% (2)
6-12 Code Set	51.4% (56)	40.4% (44)	3.7% (4)	0.9% (1)	0.0%	3.7% (4)
13-17 Code Set	48.6% (53)	40.4% (44)	5.5% (6)	1.8% (2)	0.0%	3.7% (4)



Participants were asked to review items in each of the developmental codes sets and indicate if they endorsed the set as a whole. All code sets were endorsed by a majority of the sample with a high level of agreement (i.e., endorsement levels ranged from 86.5% to 94.7%). Overall sample endorsement rates for each developmental code set is displayed in Table 18. When a code set was not endorsed as a whole, participants indicated between one and ten items that were perceived as non-essential for inclusion for the specified age group, with the majority of people indicating only one or two items from a particular developmental code set.

Table 18. *Level of Endorsement for the ICF-CY Developmental Code Sets*

	n	%	Total n
Developmental Code Set 0-2	107	94.7%	113
Developmental Code Set 3-5	102	90.3%	113
Developmental Code Set 6-12	96	86.5%	111
Developmental Code Set 13-17	96	86.5%	111

When a code sets was not endorsed the respondent typically still rated the items as good or excellent for representing critical, shared areas of functional characteristics that can be used to document assets or problems for all children regardless of health condition or disability diagnosis. For example, two participants did not endorse any of the four developmental code sets yet still rated each of the code sets as good or excellent in representation. Comments that were included under the endorsement questions generally addressed either a missing item or the need to clarify a category. No statements were

included that suggested significant problems with the code sets. Overall, the responses to the final survey indicated strong support for the four derived developmental code sets.

## **CHAPTER 4**

### **Discussion and Implications**

The primary aim of this study was to develop age based developmental code sets from the WHO ICF-CY that are applicable within a global context and can be used to facilitate international collaborative efforts in research and practice. The Delphi technique was used to obtain consensus from an international group of experts through iterative rounds of online surveys. This study demonstrated that ICF-CY categories could be distributed into reduced item sets based on expectation for functioning at four different age groups that correspond to commonly recognized developmental stages at a high level of consensus from a diverse, international sample of professionals. Four unique code sets were created and endorsed by a sample representing 27 countries and at least 13 different disciplines who work in various settings and capacities including research, clinical, academic, and administrative roles. In this chapter differences and similarities between the developmental code sets by age group will be elaborated, followed by a discussion of content validity and reliability of findings including the a review of procedures taken to assure credibility of findings. Limitations of the study are discussed and contributions to the field are presented. The chapter concludes with suggestions for applications and future research that would build on the findings and validate the utility and content validity of the final ICF-CY Developmental Code Sets code sets.

## **Terminology for Reduced Item sets for the ICF-CY**

**Code Sets Not Core Sets.** The application of the ICF in clinical practice was facilitated by the creation and implementation of “core sets” or a reduced set of items selected for a specific health condition or disease. Core Sets have been used in rehabilitation to confirm medical diagnosis in adults and items in the core sets are included because they relate to one condition. However, the ICF version for children and youth was created to address the dynamic nature of development and varying manifestations of disease or disability across children and during different developmental periods.

Simeonsson (2009) identified the following reasons why application of a disease based or diagnosis based reduced item classification set for children would be problematic. Core sets would be limited in use for comparative documentation of functioning. ICF Core Set items were selected to characterize particular medical conditions (Cieza, et al., 2004; Stucki et al., 2004). Core sets represent only one health condition by definition. The ICF-CY provides a standard for classifying dimensions of functioning and disability regardless of underlying cause (Simeonsson, 2009). Moreover, there is variability in child functioning within a given diagnosis and significant overlap in functional limitations or participation restrictions among diagnoses.

In addition, childhood diagnoses may change over time. A delay in a developmental domain may only be present temporarily or become a more permanent issue. While adult characteristics are relatively stable, children experience changes in body structure and functioning and acquire skills at different rate so it can be difficult to distinguish delay from limitation. In addition, “the younger and less mature that the child is, the greater the

challenge has been to defining disability” (Simeonsson, 2006 p.67). These diagnostic challenges are reflected in “Developmental Delay” diagnosis in early intervention and special education category. Finally, Simeonsson identified that there is interest in documenting or describing childhood functioning beyond diagnosis supporting the need to create a reduced item set with a broader focus than to confirm or describe one particular diagnosed condition.

**Developmental Code Sets not Age Code Sets.** The proposed code sets are intended to reflect functioning for children in different developmental periods regardless of health condition or disability. This approach would allow for broader applicability than core sets that are often used to confirm specific diagnoses. The code sets could describe characteristics of children with various diagnosed conditions and allow comparison of functioning. The term “code” was substituted for “core” to reflect the conceptual difference and intended difference in application between the two types of reduced item sets.

Because the ICF-CY was designed to provide comprehensive and inclusive coverage of development from infancy to adolescence, it contains many codes that will not be relevant to a child at any given point in time. While the four proposed sets align with general developmental periods in childhood (and called “development code sets”), they are age based to define these four periods for more standardization in research. The final developmental code sets could just as easily be termed by developmental stage (e.g., early childhood code sets) as these are generally defined by chronological age range and often used as eligibility criteria for support services (e.g., early intervention services ending at 36 months). The final code sets are not referred to as “age sets” to avoid misrepresentation as a norm based measure that yields same age comparisons. Rather, code sets represent ranges of age to

reflect the variability in attainment of developmental milestones and more general shared life situations and functional expectations.

The four developmental code sets were created according to commonly recognized developmental stages (i.e., infancy and toddlerhood as birth to 36 months, early childhood as 3 to 6, middle childhood as 7 to 12, and adolescence 13 through 17). The age ranges for each group also aligns with different eligibility criteria for medical and special educational services in the United States. This approach is supported by health promotion research in that “the patterns and distribution of children’s health influences are age specific....a child’s development occurs explosively in the first years of life, gradually becomes slower with advancing age, and again accelerates during adolescence, so that their relative salience varies with age or developmental stage” (National Research Council and Institute of Medicine, 2004, citing Bogin, 2001). Indicators of functioning were selected from the ICF-CY for the domains of Body Functions, Activities and Participation, and Environments after a review of research and findings from ICF-CY field trials. The Body Structure codes were not included; problems in these areas could be captured with additional codes if needed. Identifying which structure codes would be essential to include was not an appropriate question based on age or developmental expectation.

### **Constructs Represented in the Developmental Code Sets**

The content of developmental code sets was compared to developmental theory to determine if final items were consistent with general developmental expectations. This section describes the general areas represented by each code set, comparison of content to

developmental theory, and an example of validation efforts for an age group by setting expectations (i.e., the 3-5 code set and state level early childhood learning standards).

Participants rated early learning, mobility, and communication items in the early childhood code sets as most important. For the infants and toddlers, items that were rated as most important are consistent with early developmental milestones for expected cognitive, receptive and expressive language, social, and motor skills (e.g., sensory exploration, playing with objects, vocalizing, understanding communication, sitting independently, and use of hands and arms to obtain objects). One item that dropped between the second and third round surveys was walking independently (“walking indoors or outdoors”), which 22% of the sample rates as somewhat important. Although this item is common in early developmental screening of gross motor skills, an item representing general mobility (“moving around, e.g., crawl, scoot, climb stairs, jump”) was rated as essential by approximately 73% of participants.

Although the developmental code set for the early childhood group (3-5 code set) also addresses early learning, play, and mobility, almost half of the Activity and Participation items are related to communication and language development (i.e., 7 items compared to 2 in the 0-2 code set). Items rated as essential include speech, understanding spoken language, using and comprehending nonverbal messages/communication, and ability to engage in conversations. Items representing adaptive skills for toileting and eating routines were also present.

In middle childhood, the focus on social skills included items for personal responsibility in interpersonal interactions, including creating and maintaining relationships. There was also a shift from mobility and communication to learning, managing daily tasks,

stress, and routines, self care, and learning academic concepts and skills such as reading and calculating. In general, more items on interpersonal interactions were rated as essential for the middle childhood and adolescent developmental code sets (i.e., three relationship items for the 6-12 code set and 4 items for 13-17 code set). In the adolescent code set (13-17 age range), an expectation for an increased ability to take care of oneself and an ability to assist others and perform social roles was included. There was also a continued emphasis on academic learning and autonomy for this age group.

## **Reliability and Validity of Results**

### **Study Design**

Deriving code sets that are appropriate for multidisciplinary and international use required a research method that elicited expert opinion and study involvement from individuals who represent the professionally and geographically diverse intended users of the ICF-CY. To accomplish this goal, individuals from different disciplines, cultures, and professional settings had to prioritize and come to agreement about which ICF-CY items in the Activity and Participation, Body Function and Environment domains were appropriate and essential to include as a minimal reduced item age-based code set. Obtaining expert consensus of essential items occurred in successive steps. An online Delphi survey method was determined to be the best approach to create code sets using an iterative consensus process with an international sample.

**Appropriateness of the Delphi Technique.** For the current study, the Delphi technique was used to obtain consensus from a diverse international sample of 151 professionals about essential ICF-CY items to include in code sets. Using a series of three



iterative online questionnaires, a high level of consensus was reached about the most important items to include for different age groups, and findings enabled the creation of four brief classification sets of key indicators of child health, functioning and development derived from the ICF-CY.

The Delphi technique has been supported as a “well-recognized and commonly used approach for gathering validity evidence using expert panels” within the measurement field and as a reliable technique to obtain consensus of experts (Biondo et al., 2008, p. 936). The research method for the study was consistent with recommended practice for the Delphi technique, by eliciting anonymous feedback from a panel of experts who are knowledgeable in a specialized area using series or rounds of surveys (Biondo, Nekolaichuk, Stiles, Faisinger, & Hagen, 2008). Further, this method has been successful in the derivation of adults IFC cores sets in efficiently creating brief tools that are meaningful and increase the accessibility and application of the ICF.

**Reliability of Findings.** Consensus results achieved using a Delphi procedure are only as credible as the sample. While knowledge about survey design and efforts to maintain transparency in analytic decisions are necessary when using this research method, the generalizability and credibility of results are defined by the study participants. “The number and representativeness of participants will affect the potential for ideas as well as the amount of data to be analyzed (Hasson, Keeney & McKenna, 2000, p. 1010)”.

One of the strongest aspects of this study is the diverse and accomplished international sample. Considerable effort went into participant selection and recruitment efforts to achieve adequate representation of cultures, disciplines, and settings. In addition, the retention rate of the sample was quite high. One hundred and sixty individual emails were

sent between rounds one and two, to provide participants with a summary of findings and document with their own responses for comparison. In addition, group email reminders were sent to remind participants to complete surveys and to thank them for their time and contribution to the study. Considering that no compensation was offered apart from a copy of the final code sets, the high response rate and high retention rate provide evidence for the credibility of results. Regarding transparency, the analysis was sent to participants between rounds as well as a clear statement of how exclusion decisions were made, so that no question remained about how decisions were achieved in the determination of consensus from opinions.

In addition, a majority of the participants had the highest level of training in their respective fields and many are established as experts with extensive experience as clinicians, researchers, and professors knowledgeable in therapy and practice. Given the background and experience of the dissertation advisor in international work and as co-chair of the ICF-CY workgroup, it is certain that many of the international experts participated in the study because his involvement provided credibility to the study. The online format provided anonymity so that no one person could influence individual ratings (as possible during in person focus group or collaborative problem solving efforts). This was important given the variable familiarity with the ICF-CY reported by participants and background of participants who might be readily deferred to if opinions differed. Finally, the final endorsement was provided by almost all of the participants, with the majority also rating the developmental code sets as excellent in representing essential characteristics of functioning for each group.

**Cultural Bias in a Global Taxonomy.** Including an international sample requires additional procedures to determine if language differences would reduce the reliability of the

findings. One of the most important contributions of the ICF-CY is the possibility of global application as the ICF-CY is designed for use in all countries and settings. The philosophical tenets were based on the UN Rights of the Child (23) with the assumption that there are universal principals important for all children regardless of health status and country of origin.

The ICF-CY workgroup piloted items in several countries to evaluate application and reduce cultural bias. Experts from 23 countries participated in the design activities including examining terminology, conceptual sources, and classification approaches (McLeod & Threats, 2008). These scholars also represented different professional backgrounds and training including psychology, education, occupational therapy, speech-language pathology, rehabilitation, and medicine.

Because the ICF-CY went through extensive field testing in Italy, Japan, Sweden, US, Sudan and was designed with feedback and contributions from scholars from 23 countries prior to the WHO endorsement, problems with cultural bias have been minimized such that ICF-CY items are intended to be universal (McLeod & Threats, 2008). In addition, field trials in Sweden included examining feasibility of the ICF model for clinical practice in Russia, Pakistan, China and Nigeria as well as research that asked practitioners to rate cultural sensitivity of items (Björck-Åkesson et al., 2010). In addition, building on the work of the I-CY HAB forms was also important to increase code set reliability and demonstrate consistency with items that were found to be important for clinical practice.

**Content Validity.** A review of specific items for each code set broadly supports developmental theory. Final code set items appropriately reflected increasingly complex and advanced functions for all developmental domains (i.e., cognitive, motor, adaptive, social-

emotional, and language / communication functions) as child age increased. The items retained in the different age groups align with general age based developmental expectations; no major violations were found regarding too advanced or inappropriate behaviors, skills, or functional characteristics for a child within the different age range categories. There appeared to be appropriate overlap with some functional items across age groups, although no items in the body functions and activities and participation domains were rated to be essential for all age groups.

Context items were rated by the international group of experts as essential to include in code sets. This suggests an important shift in the way disability is now conceptualized globally. In fact, environmental items were endorsed at a level similar and sometimes more than items in other domains. Interestingly, the number of environmental codes was lowest for the group of children under three, who are generally most dependent on others and environment for functioning.

**Consistency with Developmental Theory.** ICF-CY Developmental Code Set Items also appeared to generally align with developmental theory regarding expected skills, functions, or characteristics. Various theories about the developmental process of learning have been hypothesized and tested over the past several decades. The ICF-CY was designed to reflect both an ecological perspective and dynamic, transactional process where development and functioning proceeds through interactions of a child and environment. The final ICF-CY Developmental Code Sets maintained this framework as items from all three domains were retained. In fact, environmental items represented between 1/5<sup>th</sup> to 1/4<sup>th</sup> of the final times retained in the code sets (21.6% for the 0-2 set, 21.7% for 3-5 set, 32.8% for 6-12 set and 34.6% for the 13-17 set).

In addition, content in the code sets are consistent with Piaget's research and theory that provides a framework for expected behaviors during different ages or developmental stages. Jean Piaget's work remains highly influential in present understanding about changes in the process of childhood learning and reasoning (Piaget & Inhelder, 1969; 2000). Therefore, an examination of Piaget's developmental expectations and conceptually related items in the ICF-CY Developmental Code Sets can provide yet another measure of the validity of expert ratings regarding appropriateness of expectation for functioning within a general age range.

In general, items in the Activity and Participation and Body Functions domain identified as essential were consistent with behaviors and skills outlined in Piaget's theory. Items retained in the 0-2 code set reflect developmental expectations proposed in the sensori-motor period including reflexes of the newborn from automatic to conditioned, sensory exploration, grasping and manipulating items, and object permanence. Specifically, items in the infant and toddler code set included the following items: exploring objects by mouthing, touching, tasting or smelling, watching and listening to engage in purposeful sensory experiences, learning through actions with objects, vocalizing when another person is in the proximal environment, using hands and arms, differentiation of familiar persons, moving around, playing. The Body Functions items retained also reflect an emphasis on sensory functions (e.g., seeing, hearing, touch, pain, voice functions) and motor functions that allow an infant or young child to learn by play or performing actions on objects (e.g., spontaneous movements, motor reflexes).

In the early childhood developmental code set (3-5 age group), items also broadly aligned with developmental skills proposed in Piaget's developmental theory. Symbolic

representation is a primary cognitive skills for the preschool age child, observable in language and pre-literacy behaviors. In the code sets, this was well represented with half of the Activity and Participation items related to language and communication functions. In addition, items regarding engagement in preschool, acquiring basic cognitive concepts, and adaptive skills were included recognizing the growing areas of context often seen within this age frame.

The middle childhood code set (6-12 age group) included items that were functionally more complex than the early childhood items for all areas of development (i.e., cognitive, social and communication, motor, and adaptive functions). Concrete operations necessary to perform mathematics and problem solving were captured by the inclusion of cognitive and academic items that identified both learning to calculate and calculating, thinking, and problem solving. Attention, memory, and thought functions were included at the body level as well as articulation, fluency and specific mental functions. The adolescent code sets included items that would document formalized thought such as thought functions (including goal directed and logical thoughts) and solving problems as well as reading, writing, calculating, and thinking.

**Code Sets and Educational Standards.** The ICF-CY Developmental Code Sets can be useful in different settings. Although the ICF Core Sets have primarily been developed and used within the rehabilitation setting, it is important to examine how the ICF-CY Developmental Code can be applied in different setting that aim to promote and document child functioning and development. One of the major roles for children in many societies is to be a student who performs successfully in a school environment. Expectations for children's learning are both conceptual at the policy level, and applied such as for setting

kindergarten entrance requirements, criteria for educational success, and curriculum decisions. In the past decade, education standards have been initiated at the state level for children in preschool. Practitioners and policymakers have established early learning standards to represent expectations about the knowledge, skills, and characteristics children should demonstrate before starting formal schooling in kindergarten (Scott-Little, Kagan, & Frelow, 2006). According to a review and content analysis performed by Scott-Little et al., (2006) examining 46 state documents of standards, there is considerable variability in standards selected across states, most tend to be focused on academics with little emphasis on areas of functioning other than language and cognition.

In a nationally representative longitudinal study (Early Childhood Longitudinal Study, Kindergarten, ECLS-K), teachers reported that being physically healthy, rested and well-nourished, able to communicate, and being enthusiastic and curious in approaching new activities were the most essential qualities for children to be ready for kindergarten (Hair et al., 2006). The following five domains of development were identified by the National Education Goals Panel's Technical Planning Group on School Readiness as important to a child's preparation for school: physical well-being and motor development; social and emotional development; approaches to learning; language usage; and cognition and general knowledge identified (Zill & West, 2001). However, this framework does not appear to be reflected in the emerging early learning standards proposed for preschool children in the US.

**Early Learning Standards and the ICF-CY Code Sets.** A comparison of dimensions noted in the early learning standards and those identified in this study found primary differences related to adherence to an ecological conceptual model for the ICF-CY developmental code sets. No items were reported that concerned environmental factors in the

state standards, despite the broader conceptualization of school readiness that has been proposed by many researchers and early childhood organizations (Scott-Little et al., 2006). This broadened view reflects an ecological perspective extends the focus from a lack of skills or knowledge within a child, to include context or environmental variables (e.g., capacity of families, early education programs, and community as well as schools adaptation to successfully educate children entering with different abilities and experiences).

In comparison to items in the early childhood code set, domains in state early learning standards tended to be more academically oriented, despite “a long-standing and rich research literature from the medical, educational, and developmental fields has established that a child’s physical health and well-being lays the foundation for future development and learning” (p. 165). Few early learning standards on physical health and social-emotional development were found in many of the state early learning standards. Investigators reported that each state has its own standards due to “the fragmented nature of the early care and educational system” (p. 167). They questioned how much variation is acceptable and the role of research and theory to guide the development of standards.

**ICF-CY Conceptualization for Early Learning Standards.** Children enter formal education systems with differences in background and early experiences. Varying experiences and resources available in early childhood have been differentially related to children’s preparedness for school entry at Kindergarten and subsequent academic achievement in later grades. Recent conceptualizations and proposed strategies to measure problems learning or applying knowledge reflect a broader philosophical shift in viewing child disability as no longer existing exclusively within the child, but rather as a manifestation of ongoing dynamic interactions between a child and his or her environment.



The method of measuring child learning within the ICF-CY framework would include documenting environmental and relational factors that would promote or hinder optimal functioning. This type of approach would include examining situational factors, personal factors, cultural, and environmental factors that might facilitate or impede the learning process.

The ICF-CY Developmental Code Set (3-5) includes 18 environmental factors and 16 body functions. Environmental items included products and technology for play, education, and communication. Body functions relate to areas of functioning in sleep, attention, memory, perceptual, motor skills related to muscle tone and balance, as well as sensations of pain, heart, immune, respiration, growth maintenance, eating and drinking, toileting, and production of sounds. What appears to be excluded is a code specifically related to the relationship with teachers and childcare providers. Although the related environmental category from the ICF-CY (i.e., people in positions of authority) was included in the initial survey, it did not remain in the final code sets for the early childhood and middle childhood age groups. The item may have been rated differently if teachers, educators, or caregivers were separated out, although the item would be inconsistent with the ICF-CY.

### **Limitations and Future Direction**

Validation studies are needed to explore the application of the developmental code sets in practice in a variety of settings. In addition, feedback from parents and children would be an important follow-up study, particularly if these code sets are used to create age based developmental screening instruments or tools to document and monitor intervention outcomes.

## **Study Limitations**

While the participants in the sample represented several countries and disciplines, the study results would have been greatly enhanced with more participation from professionals working in other countries. “The results of any consensus process may differ with different groups of experts” (Stucki et al., 2004, p.112). Therefore, validation studies are required for these code sets. In particular, better representation from professionals in Central and South America, Middle East and Africa would provide stronger assurance that the developmental code sets are appropriate and adequate for worldwide use. In the same way, increased participation from clinicians and parents would provide increased likelihood of reliable and adequate content coverage. According to procedures confirmed by the IRB all sample participants were required to reply to the official detailed invitation (see Appendix A). Unfortunately, there were a few eligible participants from countries that were ultimately not represented (i.e., Brazil, Costa Rica, Pakistan, and Lithuania) who indicated interest in the study, but did not respond to the official study invitation to receive a link to the online survey. Given the importance of global representation in the study, it would have been beneficial to pursue follow-up with these potential study participants or obtain an IRB amendment that would have allowed a conditional modification to the informed consent process. Future efforts may include validation studies of each age set by experts who primarily work within a given age-based population of children.

The final sets of developmental code set items were not validated through focus groups or comparison with existing measures and professional standards for education or health care policy. Linking items on the developmental code sets to existing measures and

professional service guidelines would validate the overall content and provide suggestions for how to apply the code sets for assessment and evaluation efforts. In addition, analyses that compares dimensions rated by professionals as essential to represent child functioning with existing state and federal regulations and identified goals for various disciplines represented would anchor the items in relevant policy. Another important step for validating and applying the study results is to compare items on the developmental code sets to existing standards in education, information collected in health information systems, and existing valid and reliable measurement instruments.

Overall, the responses to the final survey indicated strong support for the four derived developmental code sets. The developmental code sets were not only endorsed by almost all of the participants, all of the code sets were rated by the majority of the sample to have good representation of critical areas of health, functioning or development, with three of the four sets rated to have excellent representation.

### **Study Contributions**

As there are more than 1,600 codes in the ICF-CY, identifying a smaller number of codes that could serve as a minimal set for reference in research, policy or clinical applications with children can contribute to the worldwide application of this universal system. By introducing the ICF-CY through a short list of essential indicators a clinician or researcher may be more inclined to try to incorporate ICF-CY items into practice. The results from the current study provide standard brief tools that can be used to promote the ICF-CY as a shared language of functional codes to help clinicians, researchers, and policy makers

communicate about children's functioning using common developmental indicators regardless of professional discipline or nationality.

Findings from this study can contribute to the application of the ICF-CY by providing researchers, policymakers, clinicians, and administrators a reduced number of categories (between 37-60 items) from the ICF-CY representing essential characteristics of children's functioning at different ages to use as a standard minimal for documenting children's functioning. The relatively brief list of items could serve as minimal information collected in multidisciplinary research or clinical practice. They could provide a standard set of items and common framework that a multidisciplinary team could use to monitor change, identify environmental barriers, or determine functional priorities for children and families. Providing a shared starting place for information systems will allow better comparison of consequences of health conditions and understanding about children's functioning when given different disability diagnoses and promote a unified conceptualization of childhood disability. In keeping with the goals of the ICF-CY, these code sets would encourage consideration of a children's participation in their daily lives and examination of external barriers or resources that promote successful involvement in social roles or activities.

This study also introduced the ICF-CY as a new global taxonomy to an array of influential practitioners, researchers, and policy makers in several countries. Specifically, 16% of the participants indicated that they were not at all familiar with the ICF-CY and 60% of the sample had never used the ICF-CY. Because the ICF-CY is a new classification system there is limited awareness about the purpose and many potential uses; this study helped to promote the application of this system and add to professional understanding.

ICF Core Sets provide a common standard for data collection in research about a particular health condition and as such may contribute to the “quality, readability, and comparability of studies” (Stier-Jarmer, 2009, p. 33). They provide a standard for what information should be included when describing a particular health condition. The ICF Core Sets, such as the ICF Core Sets for Low Back Pain, have been demonstrated as useful for outcome and rehabilitation research, clinical practice, and health status (Stier-Jarmer, Cieza, Borchers, & Stucki, 2009). At the system level ICF Core Sets have been proposed for use in health reporting, health statistics, bench marking, and case management (Stier-Jarmer et al., 2009). The ICF-CY Developmental Code Sets can also be considered for similar applications. Items were rated as essential within all three major ICF-CY domains (i.e., Activities and Participation, Body Function, and Environment).

### **ICF-CY Developmental Code Set Applications**

The ICF-CY Developmental Code Sets have several potential applications and contributions for advancing evidence-based practice, promoting a holistic view of child functioning and disability, encouraging assessment and intervention efforts that identify environmental factors as treatment targets and outcomes. The next few sections outline areas in the field that have been identified as areas for future application of the ICF-CY classification system and describe how findings from this study can contribute to each identified area.

**Advance Evidence-Based Practice.** Simeonsson (2009) identified the following eight ways that the ICF-CY could be used to advance evidence-based practice: (1) as a basis for differentiated assessment; (2) emphasize collecting profiles of individual child functioning;

(3) clarify clinical diagnoses, dual diagnosis/co-morbidity; (4) support service delivery that is provided on the basis of functional profiles rather than administrative categories or medical diagnoses; (5) enhance the correspondence between assessment and intervention planning for an individual child; (6) offer codes to identify intervention outcomes; (7) document the gradient and hierarchy of change in functioning as evidence for progress; and (8) generate summary statistics of children or populations defined by functional characteristics.

(Simeonsson, 2009, p. 72). The final four ICF-CY Developmental Code Sets could be used to help accomplish any of the eight identified goals for advancing evidence-based practice and promote a bio-ecological conceptual model of disability that can describe children's functioning in everyday life.

**Application to treatment outcomes.** Stier-Jarmer et al., (2009) noted, “outcome measures, especially those addressing functioning and disability, usually rely on an underlying conceptual model” (p. 29). The ICF-CY developmental code sets could contribute to the growing endorsement of the ICF conceptual model based on child functioning rather than disablement when used to identify and record intervention outcomes. Including classification items at the body, person, and environment level promotes a holistic view of child health and functioning. Information describing functioning in context encourages consideration about modifiable environmental targets for intervention and facilitate the selection of appropriate goals to support children participate successfully in their daily life situations enhancing meaningful and individualized service delivery.

## **Future Direction**

This study provided a unique opportunity to contribute to the worldwide application of the ICF-CY. The results from this study are intended to contribute to the implementation of the ICF-CY taxonomy by reducing the time necessary to evaluate and determine critical dimensions that need to be considered, thereby facilitating the translation of this tool into practice. Publication or dissemination of the findings from this study would promote the ICF-CY shared conceptual model of health. These internationally agreed upon code sets could help advocate for and guide the development of new instruments that align with the international ICF-CY. Future efforts may involve targeted validation studies for the consensus of these items and translation of the items into an accessible multidisciplinary developmental screener or functional outcomes checklist.

One step toward initiating follow-up validation studies involved creating a website to post the developmental code sets to make them available for the study participants and other interested individuals. Participants were told that they would receive a copy of the final code sets. An email with a link to the following website was provided to all study participants ([www.icf-cydevelopmentalcodesets.com](http://www.icf-cydevelopmentalcodesets.com)). Final code sets are available for review and use with PDF files available to be downloaded. Individuals who use these are asked to indicate how they used the code sets and provide feedback so that documentation can be maintained.

**Contribute to Research on Intervention Outcomes.** Two areas of future work with the ICF-CY involve identifying reliable and valid instruments to differentiate activities and participation, and examining the feasibility of the ICF-CY to evaluate programs and intervention outcomes (Björck-Åkesson et al., 2010). Linking rules were created to facilitate the systematic linking of ICF categories and measures (Cieza et al., 2004). The ICF can serve as a common reference framework and connect measures and interventions. Outcome

measures used to evaluate treatment should “at least have to address specifically the aims with which interventions are applied (Cieza et al., p. 213)”.

Without a universally agreed upon conceptual model of functioning and disability there may be a large number of outcome measures which differ in the areas of functioning they are intended to address (Stier-Jarmer et al., 2009). “Outcome measures, especially those addressing functioning and disability, usually rely on an underlying conceptual model. (p. 29).” The ICF integrates the biomedical and societal models as a universal reference and exhaustive classification to address the impact of a health condition on functioning (Stier-Jarmer, et al. 2009).

The findings from this study can be directly applied to extension and validation studies. Examples of options for the application of the developmental code sets in future research are presented next. The proposed studies could inform future measure design using ICF-CY items, identify challenges and benefits to using a shared set of items, inform how forms could facilitate communication and team collaboration and enhance quality service delivery.

One important future activity for the ICF-CY is to develop instruments or identify measures that can inform the application of severity qualifiers to codes (Simeonsson, 2009). The developmental code sets can contribute to this endeavor by providing a first step for developmental screening measures. For example, validating the <3 code set and designing a measure that could be used to document functioning, capabilities, and environmental resources at children’s entry into early intervention and at exit would be useful to evaluate outcome based on type and intensity of services relative to range and severity of identified problems.



**Develop Comprehensive Developmental Code Sets.** ICF Core Sets in rehabilitation include both brief and comprehensive versions. The number of ICF categories for each varies, but can be as few as nine in a brief core set and as many as 93 (e.g., ICF Core Set for obesity). Extending the findings from the current study on developmental code sets could occur by obtaining endorsement from experts who work with specific populations of children by age. These studies would validate and increase the utility of each developmental code set or determine other essential items that should be added. For example, conducting a Delphi study with select groups of professionals who work in early intervention may provide additional comments or items that would be beneficial to include. To that end, four separate extension studies could be conducted with each study examining one age-group. Using the same procedure, additional items could be added or additional specificity of items could be included so that “comprehensive developmental code sets” could be created.

The content of developmental code sets could be examined by different disciplines. Focus groups with groups of professionals by discipline or interdisciplinary would allow further examination of item representation. Although the item sets generally align with research on important functional skills, areas of participation, and age based developmental expectations for the code sets, there were a few items that may have been prioritized had the sample included a different distribution of professional backgrounds or service settings due to salient populations of children supported. Focus groups with parents and children would provide an important perspective regarding the items derived in the current study. This research method is also consistent with the ICF Core Set validation procedure.

**Examine Utility for Collaboration in Service Delivery.** According to Lollar (2008), "the ICF-CY gives medical, educational, child care, and other relevant clinicians and

researchers a systematic approach for understanding and communicating about functioning in children and youth (p. 21)”. Research could also be conducted to examine service provider attitudes about usefulness of the tool regarding team communication, comprehensive care, increased understanding about child functioning, and influence of this process on quality of service delivery and coverage for families and children. An extension of this is to have separate forms for each of the team members to use that are similar but completed separately to examine differences in application and comparison of how these items were assessed and addressed in treatment. In addition, creating a corresponding parent questionnaire that would provide parent feedback would enhance family centered care. For example, code sets could be prepared survey format to ask parents about each area of functioning for priorities, problems, and observed change before, during, and after an intervention in a formative and summative evaluation process.

## **Conclusion**

Promoting the health and development of children requires more than the identification of problems or determination of a disability diagnosis. Appropriate understanding about modifiable indicators of functional risk factors is crucial for prevention and early intervention efforts and the reduction of prevalence in secondary conditions. However, the variability of approaches to define childhood disability presents a significant challenge for health promotion, service integration, and reliable comparisons of health status data (Simeonsson, 2009). These issues have been addressed with the WHO endorsement of the ICF-CY.

The ICF-CY is the first universal classification system of child health. It provides a common framework and language to document functioning at the body, person, and social levels for children birth through seventeen years of age. Until the ICF-CY, there was no standard framework available to document child health and development. However, “for the first time...there now exists a universally agreed-upon conceptual framework and classification for functioning, disability, and health (Stier-Jarmer et al., 2009, p. 36)”. The ICF-CY has multiple purposes such as use in policy planning, surveillance, and documentation of intervention outcomes. The ICF-CY provides a common language and shared conceptualization across professional discipline and countries for universal use in health, education, and social sectors (Ibragimova et al., 2005). Application of the ICF-CY for research, practice, and policy is important to unify data on child health status and functional characteristics, but it is limited by the complexity and comprehensiveness of the over 1,600 category system.

Past efforts in children’s health promotion have been limited by the lack of agreement about the conceptual model that should guide documentation and classification of health status and childhood disability. The National Research Council and Institute of Medicine (2004) advocates for health promotion and better models to understand child health, and “conceptualizations of health have generally not considered development as part of health... and new measures need to be developed that capture the multidimensional nature of children’s health” (p. 12). A global classification system could provide opportunities for greater communication across disciplines and across countries. This will increase reliability of data comparisons of child health and allow consistent measurement of the manifestations of disease or disability. The National Research Council and Institute of Medicine (2004)

advocates developmental and functioning indicators in future models of health. Specifically, the council called for “future systems need to incorporate a refined conceptualization of children’s health that considers prominent developmental characteristics of children as well as positive aspects of health, and they should include new methods for assessing both children’s health and its influences”(p.1). In addition, the ICF-CY provides a common framework to capture environmental factors already established in the literature to influence development and functional outcomes and yet seldom incorporated into disability documentation or intervention planning.

The ICF-CY Developmental Code Sets derived in this study are abridged sets of key functional dimensions of development intended to reduce the time necessary to understand and use the ICF-CY model and categories. They are intended to increase the feasibility of applying the ICF-CY model in clinical, research, and policy work. The developmental code sets may also enhance future interdisciplinary work by increasing continuity of health and disability classification across service settings to document problems. They can be used to inform the design of effective local intervention strategies for individual children or facilitate discussions about children during collaborative multidisciplinary care. The common framework and language could also allow shared service delivery goals that reinforce family prioritized developmental or functional areas for a child or to allocate different intervention targets to different clinician or team members. Finally, the derived code sets can potentially contribute to the future design of measurement tools and research by providing a common conceptual model to document functioning and change.

Reference to the ICF and ICF-CY, the developmental code sets will direct clinicians and researchers to examine and describe child disability with functional characteristics within

context and multidimensional format. Application of ICF-CY code sets will facilitate the integration of the ICF-CY framework and ecological model that encourages inclusion of environmental factors in diagnostic assessment and intervention planning. Although code sets are comprised of a fraction of ICF-CY items, the domain structure, language, and application process are similar.

The ICF-CY is the first unifying framework to document child health that attempts to describe the effects of context on child functioning and includes several environmental factors to examine as facilitators or barriers when recording profiles of child functioning. Facilitating the ICF-CY as a model and shared system for work in childhood disability will enhance global understanding about how to best support the development and health of children. The results of the current study are expected to increase the utility and accessibility of the ICF-CY by providing brief essential developmental items by child age for use in research, policy, and practice. With further validation efforts, the ICF-CY Developmental Code Sets derived in this study could offer a standard guide that would allow reliable comparisons of treatment or intervention outcomes across children, programs, even countries whereby informing system level decisions for prevention of secondary conditions, and promote the health and functioning of all children.

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