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TUTORIAL AND SYNTHESIS ARTICLE

Communication, Disability, and the ICF-CY

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Abstract

The child's interactions with persons in the proximal environment constitute the context for development of communication. Within early close relationships, the child acquires communication skills; developmental outcomes are defined by the continuous dynamic interactions of the child, the experiences provided by the family and close environment, and the use of different means of augmentative and alternative communication (AAC). Communication problems manifest in a variety of ways and at different levels of severity. The nature of problems differs as a function of the child's age and diagnosed condition, the communication skills of interaction partners, and the availability of communication aids. The focus for assessment and intervention may be the child, the family, the close environment and/or the interactions between them. Clarifying these varied functions and environmental factors is crucial for appropriate assessment and provision of augmentative and alternative communication (AAC) interventions. This paper reviews issues in assessment and intervention for children in need of AAC and presents the World Health Organizations' (WHO) International Classification of Functioning, Disability and Health version for Children and Youth (ICF-CY) as a tool to enhance assessment and intervention in the AAC field.

Keywords: *ICF-CY; Communication; Children; AAC*

Communication is often presented as the most fundamental of all human achievements. Within the first year of life, the infant begins to acquire symbolic representation, that is, the ability to represent an object with a symbol in the form of a gesture or a sound. This emerging ability to represent objects, and subsequently experiences and feelings (the semiotic function, (Piaget & Inhelder, 1969) and the distancing hypothesis (Siegel & Cocking, 1977), serves a central role in the child's development by providing the basis for knowing and communicating information. The early markers of this achievement are the precursors of the substantially more complicated communication skills that are evidenced by adults across societies. Early forms of communication may serve as reliable indicators of later language and intellectual development. Communication is composed of several basic components, including speech structures, speech functions, and mental formulations of language, that combine in the development of communication skills.

The development of the child and the development of communication are transactional processes (Light, 1988; Sameroff & Fiese, 2000). The child's interaction with others in the proximal environment forms the basis of

acquisition of communication skills. These interactions with others constitute the arena for the development of communication. Within early and close relationships the child acquires communication skills. Developmental outcomes depend upon the child's ongoing communicative interactions and experiences provided by the family and close environment. When a child's ability to interact is limited by an impairment leading to severe problems with the expression of language, alternative and augmentative approaches to enhance communication must be taken into account. The focus for assessment and intervention may thus be the child, the family and/or the environments in which interactions occur. In many cases, technological aids for communication may be an essential addition to the child's environment. Clarifying these varied functions and environmental factors is crucial for appropriate assessment, which serves as the basis for AAC interventions.

The purpose of this paper is to (a) review documentation issues in assessment and intervention for children in need of AAC, (b) present the International Classification of Functioning, Disability and Health – Children and Youth Version (ICF-CY) (WHO, 2007) as a framework for such documentation, and (c) identify implications

for promoting communication development of children with disabilities

The need for AAC will depend on the nature and severity of the child's communication problems. The current clinical and research literature on communication problems of children and youth focuses on etiologic factors, the role of communicative interaction for developing communication skills, and assessment and intervention (working with persons in the child's proximal environment in everyday activities to enhance communicative interaction), specific therapies, and provision of assistive technology. Furthermore, the nature of communication difficulties for a child in need of AAC varies with age and diagnosis. A significant challenge is differentiating various mechanisms and functions that contribute to communication problems. The relationships of speech and language and their role in communicating with others are complex and require thorough assessment in order to identify effective interventions. Speech and language are not in themselves communication, but are elements of communication. Similarly, body movements, gestures, drawings, the use of icons and graphic systems for communication, and sign language, are not communication but rather are elements thereof. Without clarity of different levels of function, appropriate interventions may be poorly conceived or implemented improperly. Although each of these basic elements of communication is a special focus within disciplines such as speech-language pathology, linguistics, developmental psychology, special education and early intervention, the different levels of function they represent require an integrated perspective. In addition, an integrated approach calls for special professional skills of those providing the use of AAC in intervention. Such an integrated, holistic approach to human functioning has become available with the WHO publication of the International Classification of Functioning, Disability and Health (ICF) (WHO, 2001). Within the ICF, functioning and disability are framed within domains of Body Functions, Body Structures and Activities/ Participation. In addition, a domain of environmental factors classifies influences of the environment on functioning and disability including the physical, attitudinal and policy environment affecting the person.

Although the ICF provided broad coverage of human functioning, concerns have been raised regarding its limitation to document dimensions of child functioning and disability in the first two decades of life (Björck-Åkesson & Simeonsson, 2002; Ibragimova, et al., 2009; Lollar & Simeonsson, 2005; Simeonsson, et al., 2003). Among these concerns were lack of content to capture changes of body structures and functioning with maturation and developmental changes in children's activities and participation. In addition, important typical life areas of children such as play, parent-child interaction, and communication; and key contextual factors such as family, home, and school, were not adequately represented in the ICF.

These concerns resulted in the publication of a version of the ICF for children and youth (ICF-CY) in 2007, in which codes were expanded to cover characteristics of functioning and disability from infancy through adolescence.

In the ICF-CY, functioning encompasses universal human experiences that can be conceptualized and classified along dimensions of body function and structure, the performance of activities and participation in roles and situations, and environmental factors. This dimensional framework documents the interaction of a child with a health condition and the environment in a bio-psychosocial model to define disability. The component of body functions includes global mental functions and voice and speech functions, and structures such as the nervous system involved in voice and speech. The component of activity and participation covers dimensions of learning and applying knowledge, general tasks and demands, communication, mobility, and self-care. The domain of environmental factors includes codes that can document the hindering or facilitating role of the environment on the performance of the child, and includes the provision of communication aids and the communication skills of interaction partners. Personal factors are also identified as a contextual factor in the ICF-CY, but are not classified or defined.

In the development of the ICF-CY, an important focus was the development of communication within the activity and participation domain. A number of items were changed or added to take communication in young children into account (e.g., eye contact, responding to a human voice, preverbal vocalization, pointing, and using pictograms). In the domains of interpersonal interactions and relationships, additional content was related to turn taking, differentiating familiar persons, informal social relationships, and parent child relationships. In the environment section, equipment, products, and technologies used by children in play and learning were added. These items reflect the multi-dimensional nature of communication and its expression as the interaction between the individual and the social and physical environment. The interactive model of functioning in the ICF-CY is well suited to analyse and understand communication issues in AAC both for assessment and communication intervention. The ICF-CY not only focuses on the child using AAC, but also provides the basis for describing the complex interactions of the child with the environment. This key feature of the ICF-CY is also the underlying premise of clinical practice and research with AAC. At another level, the ICF-CY may enhance communication among professionals, and between professionals and parents, in collaborative and multi-disciplinary applications in assessment and intervention. As a common language, the ICF-CY clarifies the knowledge and roles in intervention collaboration (Wilder, Granlund, & Björck-Åkesson, in press).

Implications of the ICF-CY for Promoting AAC for Children with Disabilities

As a member of the WHO family of classifications, the ICF-CY offers a universal language with broad implications for promoting communication of persons with disabilities. Most conditions involving communication problems have their origin in the developmental period; thus the ICF-CY is uniquely suited to advance clinical, research, and policy work by (a) providing a conceptual framework and common language for addressing communication problems, disabilities, and disorders; (b) clarifying diagnostic and treatment documentation; (c) describing the nature and severity of communication problems through the use of functional profiles; (d) enhancing the correspondence between assessed characteristics and intervention plans; and (e) monitoring implementation of intervention and documenting outcomes.

Conceptual Framework and Universal Language

The conceptual framework and the taxonomy of the ICF-CY can be used to approach assessment and intervention efforts in AAC in an organized and holistic manner. To this end, an analysis of the components shown in Figure 1, lends itself to defining the focus of efforts and the identification of needed information. The Body Functions and Body Structures components cover impairments of physical and mental functions and are applicable to assessment and diagnosis and can complement the information provided by other classifications such as the International Statistical Classification of Diseases and Related Health Problems-10th revision (WHO, 1992) and the Diagnostic and Statistical Manual of Mental Disorders, Fourth Edition-Text Revision (DSM-IVTR, American Psychiatric Association, 2000). The component of Activities and Participation is also applicable to assessment but with a focus on defining performance aspects of communication with reference roles in communicative interaction, but also to their significance in interaction and social relationships in home, school, and community life.

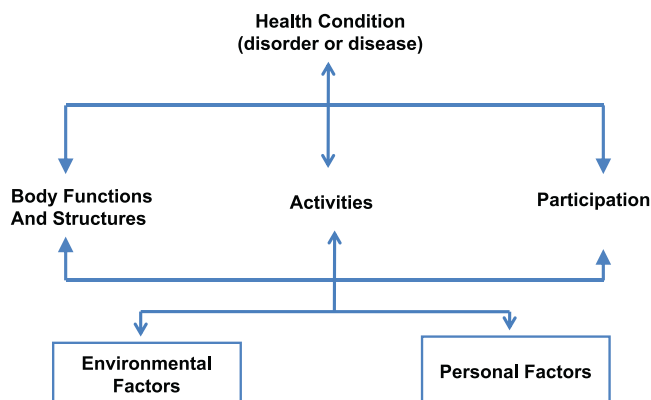


Figure 1. Interaction between components of the ICF-CY (Adapted from WHO, 2007).

The component of Environmental Factors is a unique contribution of the ICF-CY in that it offers, for the first time, a systematic way in which to document the elements of the physical and social environment that may interfere with or facilitate functioning. Of particular significance here is the framework it offers to identify and describe the influence of elements that serve to assist or augment communication of the child. In addition, these components can provide a focus in the identification of tools and instruments for measurement. This is an important area for application because available measurement tools are often designed to assess a defined, diagnosable problem rather than being based on a holistic framework of human functioning. Such review may point to the need for the continued development of measures of environmental factors and participation, particularly with reference to universal tools to document intervention outcomes (Adolfsson, 2011).

An important application of the universal framework and common language provided by the ICF-CY is providing uniformity for description of health, functioning, and disability in children and youth, as well as assessment and intervention. It gives a new perspective on the kind of assessment data needed and suggests innovative ways to work with that data in communication intervention. Regarding the process of obtaining assessment data, Appendix 5 of the ICF-CY manual describes the importance of direct involvement of consumers and highlights the role of parents, caregivers, and the children themselves in completing tools and serving as respondents to questionnaires. This involvement by different informants expands the types of information, knowledge, competence, and roles available for AAC intervention (Raghavendra, Bornman, Granlund, & Björck-Åkesson, 2007). The child, parents, other family members, and persons in the child's proximal environment, such as teachers and professionals involved in intervention, all have their own experiences and knowledge about the child and related communication issues. Since interventions most often are carried out in the everyday life environment of the child using AAC, information unique to her or his everyday life needs to be assessed from the perspective of the child and of other persons in his or her proximal environment (Ibragimova, Pless, & Granlund, 2007; Marshall & Goldbart, 2008; Raghavendra, et al., 2007; Young, Yoshida, Williams, Bombardier, & Wright, 1995). The child and the family are experts about the child's activity in everyday life, social interaction, and participation and the perceived availability of environmental factors. Preschool teachers, teachers, and personal assistants have unique knowledge of the child's activities and participation in preschool and school environments, respectively. Health professionals bring expert knowledge related to body functions and body structures as well as information on treatments, medications, and assistive technology influencing the child's communicative activities and participation.

Clarifying Diagnostic and Treatment Documentation

An important application of the ICF-CY is documentation of a child's problems related to language use and communication, which are frequent across disability conditions in development (Stein, Parker, Coplan, & Feldman, 2001). Although delayed or atypical communication are characteristics reflecting receptive communication problems such as Expressive Language Disorder and Phonological Disorders in the DSM-IVTR (American Psychiatric Association, 2000), they may also occur with many other mental disorders and disabilities. All of these conditions have their origin in the developmental period; thus, it would be useful to clarify differences and commonalities across diagnoses by documenting functional characteristics within a common framework. The inclusion of developmental indicators in the ICF-CY make it well suited to document the onset of disabilities and disorders in children and youth as well as their continuity into later developmental stages (Lollar & Simeonsson, 2005).

The comprehensive and universal scope of the ICF-CY can be used to define dimensions of functioning in children with different diagnoses or whose disorders have different etiologies. Because the ICF-CY classifies dimensions of functioning and not persons, classification of the nature of impairments of body structures and body functions and limitations of activity and participation of children, can complement the diagnostic information. Furthermore, documentation of environmental factors associated with limitations of functioning provides information about elements with implications for treatment and intervention. The ICF-CY can also be used in the form of code sets to profile children's developmental functioning (Ellingsen, 2011) as well as defining communicative demands of different situations (Adolfsson, 2011); for example, the demands specific to a classroom could be met by arranging the classroom in a way that enhances communicative interaction. With the increased identification of children with significant communication problems such as autism, and the challenge of meeting the needs of children's co-morbid conditions (Jensen, Knapp, & Mrazek, 2007), using the ICF-CY to document functional limitations may be particularly useful in providing intervention and care for children in need of AAC.

The domains and classification codes of the ICF-CY may also be applied to record the use of assistive technology in treatment and intervention contexts. Given the increasing awareness worldwide of disability and the associated need for services and supports, a common language for AAC would provide a standard basis for documentation. The need for such a common language has been proposed by Bauer, Elsaesser, and Arthanat (2011) in the United States, within the context of federal legislation, advocacy, public funding, and the increased demand and supply of devices. Bauer et al. described issues related to an Assistive Technology Device Classification (ATDC) that would

be consistent with elements of the US legislation and health care standards, and would be a logical taxonomy. To this end, the authors incorporated elements of the ICF framework and terminology in deriving a set of seven required classification elements that should be reviewed within an international classification, International Standard Organization – 9999 (International Organization for Standardization, 2002); two classifications from the United States: the National Classification System for Assistive Technology Devices and ATS (RTI, 2000) and the Assistive Technology Classification (Bauer & Arthanat, 2010), which is based on the ICF; and two online data bases in the US. The required classification elements were inclusion/exclusion criteria, hierarchical structure, naming conventions related to health and health-related states, and whether devices were intrinsic or extrinsic to the person and were cross- or disability specific in application.

The results of the review indicated that none of the three existing classifications or the two U.S. online databases met the requirements for a comprehensive classification of assistive technology devices. In response, Bauer et al. (2011) developed the Assistive Technology Device Classification (ATDC), which builds on the ICF framework and classification and is consistent with the requirements they developed. Specifically, in the ATDC, assistive devices are classified by "... their ability to optimise functioning by replacing, restoring, augmenting or compensating for impairment of body function(s) or body structure(s). An ATD thereby increases capacity for performance in activities and participation domains" (p.255). The classification of assistive technology devices is organized in two major divisions, (a) Health States (HS), incorporating the components of Body Structures and Body Function in the ICF; and (b) Health Related States (HRS), incorporating the component of Activities and Participation. In this format, devices to assist communication, such as cochlear implants and hearing aids, are listed at the HS level of body structure and function, whereas AAC devices are listed under HRS as disability specific ATD's. A variety of other devices for assisting communication more broadly are Braille note-takers, screen magnifiers, assistive listening devices, and sound field systems.

Deriving Profiles of Functioning

Assigning codes and qualifiers is the essential purpose of the ICF-CY, contributing a standard language for multidisciplinary practice across clinical settings and service systems. ICF-CY codes of particular relevance for obtaining a multifaceted picture of the child's communicative functioning and disability are presented in Table 1. In an AAC assessment, the focus is on capacity (e.g., what the individual is capable of doing); thus, AAC assessments usually are done in standardized test-environments or in environments unfamiliar to the individual. But those environments do not provide

Table I. ICF-CY Classification Codes Related to Communication.

Component	Codes
Activities & Participation	D110 watching
	D130 copying
	D131 learning through actions with objects
	D132 acquiring information
	D133 acquiring language
	D115 listening
	D134 acquiring additional language
	D135 rehearsing
	D310 communicating with receiving spoken messages
	D3100 responding to the human voice
	D3101 comprehending simple spoken messages
	D3102 comprehending complex spoken messages
	D315 receiving non-verbal messages
	D3150 receiving body gestures
	D3151 receiving general signs and symbols
	D3152 receiving drawings and photographs
	D320 receiving formal sign language messages
	D325 receiving written messages
	D330 speaking
	D331 pre-talking
	D332 singing
	D3350 producing body language
	D3351 producing signs and symbols
	D3352 producing drawings and photographs
	D340 producing messages in formal sign language
	D345 writing messages
	D350 conversation
	D355 discussion
	D360 using communication devices and techniques
	D6503 maintaining assistive devices
	D6603 assisting others in communication
	D880 engagement in play
Environmental Factors	E1150 general products and technology for personal use in daily living
	E1151 assistive products and technology for personal use in daily living
	E11520 general products and technology for play
	E11521 assistive products and technology for play
	E1250 general products and technology for communication
	E1251 assistive products and technology for communication
	E1300 general products and technology for education
	E1301 assistive products and technology for education
	E2500 sound intensity
	E2501 sound quality
	E355 health professionals
	E450 individual attitudes of health professionals
	E535 communication services, systems and policies
Body Functions	B1560 auditory perception
	B1561 visual perception
	B16700 reception of spoken language
	B16701 reception of written language
	B16702 reception of sign language
	B16703 reception of gestural language
	B16710 expression of spoken language
	B16711 expression of written language

(Continued)

Table I. Continued.

Component	Codes
	B16712 expression of sign language
	B16713 expression of gestural language
	B1672 integrative functions of language
	B210 seeing functions
	B230 hearing functions
	B2300 sound detection
	B2301 sound discrimination
	B2302 localization of sound source
	B2303 localization of sound
	B2304 speech discrimination
	B235 vestibular functions
	B240 sensations associated with hearing and vestibular functions
	B310 voice functions
	B320 articulation functions
	B330 fluency & rhythm of speech functions
	B340 alternative vocalization functions
Body Structures	S110 structure of the brain
	S240 structure of the external ear
	S250 structure of the middle ear
	S260 structure of the inner ear
	S320 structure of the mouth
	S330 structure of the pharynx
	S340 structure of the larynx

optimal opportunities, and the profile of performance (execution of the activity in the real world) may be quite different from capacity. One may use the concept of proximal zone of development (Vygotsky, 1978) in this context, where optimal capacity in communication is a feature of zone of development, but performance may not reach it.

Results from assessment appropriate to the questions of interest and the child's developmental level can serve as the basis for assigning ICF-CY codes and qualifiers corresponding to the impairments, limitations, and restrictions that characterize the child at that time. In addition, assessment is also needed of environmental factors that may serve as barriers or facilitators of such functioning. The resulting ICF-CY codes can give a profile that focuses on functioning, especially participation, involving factors that mediate between capacity and performance. The ICF-CY can be used to differentiate these dimensions and portray the life situation of the child in need of AAC and the proximal environments of family, home and school as a framework for individualised intervention. The use of the ICF-CY to document different AAC interventions may be particularly valuable for AAC applications to specific areas such as comprehension (Sevick, 2006), literacy (Hetzroni, 2004), and access in library use (Shepherd & McDougall, 2008).

It should be noted that the profile does not replace test results or clinical data, but rather summarizes them using a common language describing the child's functional status and corresponding needs for intervention or treatment. A profile is descriptive rather than diagnostic, and thus offers an approach to

define disability and disorder that is holistic and non-stigmatizing. Functional profiles are very compatible with service applications as illustrated in the use of ICF-based profiles for the inclusion of students with disabilities in school settings (Fusaro, Maspoli, & Vellar, 2009). The profile can provide a complementary tool to guide assessment and intervention, specifically, to identify goals in collaborative problem solving with significant others and designing person- and family-oriented AAC interventions (Rhagavendra et al., 2007).

Beyond providing an efficient way to describe the language and communication characteristics of an individual child, ICF-CY code profiles can be aggregated to portray their characteristics of groups of children served by a clinic, school system, or agency. Other applications to group data are to use codes to define items in epidemiological studies and national surveys to document population prevalence of disability prevalence (McDougall & Miller, 2003; Mudrick, 2002). In the development of these kinds of applications, it is important to identify a uniform list or set of relevant codes to describe the distribution of communication problems in the population. An example is proposed in Annex 9 of the ICF-CY. A limited set of codes that can be used to document the functional characteristics of children in four age groups has been developed by Ellingsen & Simeonsson (2011) and can be accessed at www.icf-cydevelopmentalcodesets.com. With the continuing implementation of the ICF-CY, it is likely that code sets will be developed to facilitate the documentation process for specific applications such as screening, assessment, and monitoring, in settings such as clinics, schools, treatment programs (Adolfsson, 2011).

Providing a Base for Intervention/Treatment Planning

A key contribution of the ICF-CY for framing intervention is the emphasis it places on assessment to define a child's functioning level rather than to derive a diagnosis. Too often, interventions for a child are designed to address pathological aspects associated with a particular diagnosed condition. Such approaches may not tailor interventions to take into account interactions of children within environments that are unique to them. For example, the appropriateness of an intervention for a child using AAC would be dependent upon whether the child functions in an inclusive or segregated classroom. Application of the ICF-CY framework facilitates the process of using assessment to plan and develop interventions. The profile of codes identifies the nature and extent of impairments of function, performance limitations and participation restrictions in functional terms. The basis for interventions supports or assistive devices can be identified based on documentation of environmental barriers and facilitators of functioning. The systematic identification of functional limitations within the framework of ICF-CY domains can serve as the basis for the

development of individualized interventions. The units of assessment for such interventions are the child's interaction with the environment, which informs the design of programs of supports and treatments based on the child's profile of functioning (Lollar & Simeonsson, 2005; Simeonsson, Pereira, & Scarborough, 2003). In other words, the link between intervention planning and assessment organized by the ICF-CY can focus on promoting children's skills in completing activities and their participation in important experiences and life situations.

Monitoring Intervention Implementation and Outcomes

After an AAC intervention has been developed for a child, it is important to monitor the extent to which the intervention is implemented and the outcomes are evaluated (Lund & Light, 2006; 2007). Such monitoring should be done on a frequent basis and over time so that adjustments can be made to the nature or process of the intervention if needed. Evaluation of intervention outcomes should be an ongoing process and can take the form of documenting changes in ICF-CY codes and/or qualifiers (Simeonsson & Lee, in press). Effects attributed to intervention can be documented by a shift of codes, reflecting a change in functioning; or a shift in the qualifier value, reflecting a change in the severity of functioning. A reduction in the qualifier value for a code would denote a lesser level of severity of impairment for body functions or limitations or restrictions of activities and participation. For example, a decrease in the universal qualifier for the code "Fluency of speech" from 3 (i.e., b3300.3 - severe impairment) prior to intervention, to 1 (i.e., b3300.1 - mild impairment) following intervention, provides documentation of improvement (decrease of severity of impairment over time).

Change in functioning with intervention can also be documented by recording a shift in the hierarchy of the codes, from lower to higher-level codes. For example, a child may have a moderate impairment in "Comprehending simple spoken messages" (d3101.2) but may improve with intervention to "Comprehending complex spoken messages" (d3102.2) with moderate impairment. In this case, the level of impairment remains constant but there is an increase in functioning. The contribution of assistive technology in the intervention can be documented with an appropriate code and a positive or negative scale for the qualifier. In the preceding example, code e1251.3 could indicate a severe barrier in terms of "Assistive products and technology for communication" whereas the benefit of an assistive device with intervention could be documented with e1251. +2 to indicate its role as a moderate facilitator of communication. This way of using ICF-CY-based data to monitor the child's response to intervention can be included in his or her educational, health, social services, medical, or other files as evidence of developmental progress. Such documentation would reference the child's needs for services as identified at the beginning of the intervention process, and would

provide evidence of outcomes based on documentation of the impact of interventions that were provided to meet the child's individual's needs as they were reflected in the child's profile of functioning.

Conclusion

The child's interactions with persons in the proximal environment constitute the arena for development of communication. The form of language and communication skills is acquired within a specific culture, but the developmental processes of acquisition are universal. Problems in acquiring language and communication are also universal and difficulties in communication and language use are among the most prevalent of disabilities in children. The identification of children with communication disabilities and the provision of intervention, treatment and education is recognized in national and global initiatives. As a universal taxonomy, the ICF-CY offers a common language and standards for promoting the development of communication of all children.

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