Applying the International Classification of Functioning, Disability and Health (ICF) to measure childhood disability

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Abstract
The International Classification of Functioning, Disability and Health-ICF addresses the broad need for a common language and classification of functioning and disability. A parallel need is appropriate measures compatible with the content of the ICF to document the nature and impact of limitations of function, activities and participation. The interaction of developmental characteristics and disability among children represent special challenges for classification as well as measurement. Demographic trends emphasize the need for universal measures that encompass the components of the ICF and can be used in surveillance, screening and evaluation. This paper identifies issues related to application of the ICF to measure disability in childhood; reviews approaches and tools to assess childhood disability and identifies priorities for the development of measures of functioning and disability in children based on the ICF. The development of measures should be framed within a framework of children’s rights and application of the biopsychosocial model to document profiles of functioning and disability of children.

Introduction
'A mentally or physically disabled child should enjoy a full and decent life in conditions which ensure dignity, promotes self reliance and facilitates the child’s active participation in the community’ (UN Convention on the Rights of the Child, 1989, Art23,Sec1.)

The International Classification of Impairments, Disabilities and Handicaps (ICIDH1) represented a significant achievement at that time in several ways. First, it advanced a new approach, conceptualizing disability as the consequences of underlying health conditions attributable to disease or injury. Second it differentiated these consequences at three distinct planes of human experience at the levels of body, person and society. Third, by differentiating these terms conceptually and semantically, the ICIDH emphasized that disability was not uni-dimensional but was manifested at different levels of human functioning in the form of impairments, performance limitations and the experience of disadvantage. Fourth, it provided a taxonomy in which numeric codes could be used to document the elements unique to each of the three levels with applicability for clinical and administrative purposes.

While the 1980 ICIDH raised awareness of the importance of distinguishing between disease and its consequences in the form of disability, it was an experimental document and not widely adopted as a classification. Further, there was recognition that it
was limited in a number of ways. The need to revise the ICIDH was based on considerations related to policy, concepts and application. From a policy perspective, the need for a revision of the ICIDH could be seen as reflecting the paradigm shift of disability from one based on a medical framework toward one reflecting social dimensions of disability. The disability advocacy movement was supportive of defining disability in terms of access restrictions. From a conceptual perspective, this policy shift was paralleled by recognition of the crucial role of the environment in defining human functioning. This was evident in the negative reaction to the linear and causal model presented in the 1980 ICIDH, linking impairments, disabilities and handicaps without accounting for the role of the environment. The ICIDH framework was seen as too deterministic, failing to reflect the dynamic nature of functioning and disablement. A further conceptual issue pertained to framing classification elements within the perspective of pathology. Lastly, there were at least two practical concerns. One was the overlap of content across the three levels of the classification. A second was growing dissatisfaction with the negative term and concept of ‘handicap’.

These and other factors provided the impetus for a multi-year effort to revise the ICIDH in the 1990’s. The revision process addressed the identified shortcomings of the ICIDH through the collective efforts of six collaborating centers, three task forces and representatives from various countries. Task forces addressed (a) mental and behavioural issues, (b) environmental factors and (c) children’s issues. The task force on children generated recommendations for taxonomic entries relevant for children and youth in the production of Beta 1 and Beta 2 versions of the ICIDH revision. With representatives of collaborating centres and other task forces, the children’s task force also participated in evaluation activities of the revision versions of the ICIDH. The result of the revision process was the International Classification of Functioning, Disability and Health-ICF approved by the World Health Assembly in 2001.2

An essential requirement for implementing effective health planning and intervention programmes for individuals with disabilities is a common language to document components of functioning and development. The ICF provides that common language and a universal standard to classify components of functioning and disability. Paralleling recognition of the need for a common classification has been recognition of the need for appropriate measures to document the nature and impact of these health conditions associated with personal and social limitations. The publication of the ICF provides a unique opportunity to identity existing assessment measures compatible with the content of the ICF components as well as to identity instruments that need to be developed based on the ICF framework.

The limited availability of measures based on an international taxonomy to assess functional limitations among children has been recognized.3 Given the disproportionate prevalence of disability in developing countries and the fact that children constitute the largest percentage of those with functional and developmental limitations,4 emphasizes the need for universal measures that are brief and effective for use in surveillance and screening. The purpose of this paper is to: (a) identify issues related to application of the ICF to measure disability in childhood (b) review selected assessment measures of disability in childhood and (c) identify priorities for the development of measures to assess dimensions of functioning and disability in children based on the ICF.

The revision process and development of the ICF reflected a conceptual shift from ‘a consequence of disease classification to a components of health classification’ (p.2).2 This shift is evident in an examination of the revised content of ICF. The classification encompasses functioning as universal human experience that can be conceptualized and classified at three different planes or dimensions: body function and structure, the performance of personal activities and participation in communal life. The facilitating or restricting role of the environment at each of these planes is recognized and can be classified as well. The intended uses of the ICF include: (a) advancing science through a standard nomenclature; (b) documenting intervention eligibility, implementation and outcomes; (c) promoting planning and policy initiatives and (d) defining individual rights and societal responsibilities. The ICF provides major coverage of the dimensions of body function and structure, of activities such as communication, mobility and self-care and of participation such as work and civic life. However, coverage of child characteristics is limited requiring further consideration of functioning and disability of children and their environments during the developmental years.5

ISSUES IN MEASUREMENT OF CHILDHOOD DISABILITY

A key function of a classification system is its ability to serve as a framework for the development of assessment measures reflecting the specified dimensions of that classification. The 1980 ICIDH saw some limited use in this regard, however most of the applications covered the dimension of Handicap and focused on adult populations. This was understandable given the fact that the
Handicap dimension was in fact set up as a scale lending itself to the development of measures such as the London Handicap Scale and the CRAIG Chart. The limited application of the 1980 ICIDH to measure disability in childhood is consistent with its restricted coverage of developmental and behavioural characteristics of children. The challenges of adapting the 1980 ICIDH for use with children were described in the development of an experimental scale to measure the dimension of handicap in young children. The limited utility of the 1980 ICIDH to document disability in childhood is demonstrated by the minimal coverage of indicators relevant to children and youth in regard to play, learning and functioning at home and in school and neighbourhood.

With the publication of the ICF taxonomy, reflecting a biopsychosocial model of disability, an important priority is to examine its promise as a framework for the development of assessment measures for children. In addition to its promise as a taxonomy for coding dimensions of disability, an important contribution of the ICF is that it can provide domains for assessment as well as specific variables that can serve as items in questionnaire and scale construction. To this end an examination of the ICF as a guide for measurement of disability in children requires a consideration of several issues. Three issues of relevance to this paper are, (a) differentiating components of childhood disability, (b) identifying the purpose of measurement, and (c) accounting for the mediating roles of developmental and environmental factors on childhood disability.

**Differentiating components of childhood disability**

In scientific and policy contexts, definitions of childhood disability are often characterized by overlap of health conditions, diagnoses or etiological factors. Similarly, eligibility definitions often reflect a mixture of the dimensions of impairments of body function and structure, activity limitations and restrictions of participation. Two legislative descriptions illustrate this overlap of dimensions. In her discussion of children’s needs in the UK, Braye reports that the Children’s Act of 1989 defines a child as ‘...disabled if he is blind, deaf, or dumb or suffers from mental disorder of any kind or is substantially and permanently handicapped by illness, injury or congenital deformity or such other disability as may be prescribed’. A similar framework based on a medical model is evident in the definition of children with disabilities eligible for special education in the USA. Under the 1997 Individuals with Disabilities Education act, children with disabilities are identified as ‘(a) children with mental retardation, hearing impairments, deafness, visual impairments including blindness, deaf-blindness, multiple disabilities, speech and language impairments, serious emotional disturbance, orthopaedic impairments, autism, traumatic brain injury, other health impairments or specific learning disabilities; and (b) who by reason thereof, need special education and related services’. These two definitions from the UK and the USA illustrate that official definitions designed to determine access to services often encompass multiple components of disability. Viewed within the framework of the ICF, the dimensions covered in these definitions include etiology, health conditions, disorders, impairments, activity limitations as well as participation restrictions. A more efficient approach for defining eligibility would be to focus on the component that encompasses the child’s needs for services and supports. In the above two examples, the nature of the child’s needs reflect educational and social support services. The focus for social interventions would likely entail the dimension of participation.

**Accounting for developmental and environmental factors**

Another area for consideration in applying the ICF builds on the person–environment interaction implicit in the paradigm shift from a medical to a broader biopsychosocial model of disability. As illustrated in Figure 1, a person–environment interaction model requires a consideration of the mediating role of developmental and environmental factors. A central issue is that children’s environments change dramatically across the stages of infancy, early childhood, middle childhood and adolescence. Each of these changes in the environments influences the child’s interaction through stimula-
tion and feedback. These interactions frame a developmental process of the child’s acquisition of increasingly complex skills involving actions and reactions to the physical and social environment. The influence of the environment on the child’s performance and functioning is thus particularly important to document in this phase of the life-span.

The significance of this interactive perspective has been advanced by Helders et al.12 dynamic view of disability for pediatrics, characterized by a shift of emphasis from medical diagnosis to functional consequences of health conditions. Within this perspective, the focus is on approaching children with disabilities in terms of addressing functional–developmental problems. Along a similar line, Stineman13 has proposed a model of human-environment integration consistent with a perspective of the person’s interaction with the environment. The emphasis of this model is to document the individual’s potential for meaningful physical and mental activity.

**Purpose of assessment**

As for defining the purpose for measurement, a key consideration is the epidemiological application of surveillance and screening to determine the scope of childhood disability. A primary goal of surveillance is estimation of the prevalence of disability in the population. In such applications, disability is often operationalized in terms of activity limitations, rather than impairments of body function or structures. A good example of this emphasis is the analysis of the US National Health Interview Survey data relating to childhood disability by Newacheck and Halfon.14 In that study, disability was defined in terms of limitations in major activities of play for preschool children and school performance for older children respectively. Based on these definitions, results indicated an overall prevalence rate of childhood disability of 6.5%.

Another example of an epidemiological approach has been described by Hogan et al.15 who obtained estimates of functional limitations among 5–17 year-old US children using data from the 1994 National Health Interview Survey on Disability. With measures based on combinations of items, estimates of disability were 12% for any limitation, 10.6% for learning, 5.5% for communication, 1.3% for mobility and 0.9% for self-care. It was also found that 3.5% had two forms of activity limitations and 1.1% had three or more. In a subsequent study, incorporating additional national survey data, Hogan et al.16 demonstrated that children with functional activity limitations experienced higher rates of unfavourable outcomes (limited family resources, poorer health status, less healthy environments and limited access to health services).

In an international context, Durkin et al.17 have developed a set of 10 questions to estimate the prevalence of childhood disability in several developing countries. The Ten Questions measure included such areas as seeing, hearing, walking and communication. Information was typically obtained from the mother or the primary caregiver as the most knowledgeable informant. The Ten Questions survey has been administered in a number of countries including Bangladesh, Jamaica and Pakistan. Representative findings from studies in Pakistan17 and Bangladesh18 have yielded prevalence estimates 1.9% and 0.9% for serious mental retardation. The prevalence estimates for mild mental retardation were 6.5% and 1.4% respectively. While the validity of the estimates was not questioned, differences in prevalence between the two countries were considered to reflect possible differences in mortality rates and cultural factors such as consanguineous marriages.

Screening in order to identify children with disabilities constitutes a related purpose for measurement. Developmental screening is designed to identify children for early intervention to promote the child’s development and reduce the risk for later disablement and secondary conditions.19, 20 In a comprehensive review of literature on this topic, Sonnander21 found that developmental screening typically involved children around the age of four with follow-up made in the first year of school. The rate of identification ranged from 1–6% with predictive rates for sensitivity (45–72%) being lower than those for specificity (77–99%) of screening. While screening can identify children for intervention, Sonnander concluded that the process is complicated by the dynamic nature of child development and screening instruments that are inadequate in capturing the complex nature of the child’s functioning. Selecting items for screening that are sensitive indicators of disability in development is an important task in applying the ICF for epidemiological purposes.

**NEED FOR MEASURES OF CHILDHOOD DISABILITY FOR USE WITH THE ICF**

**Existing measures of childhood disability**

A wide range of measures have been developed to measure aspects of disability of children, some developed to assess the impact of specific conditions and...
DEVELOPMENT OF MEASURES FOR USE WITH THE ICF

As a World Health Organization classification, the ICF serves as the global standard for defining and documenting disability. With the expanding emphasis on evidence-based health care in industrialized and developing countries, there is a corresponding need for functional assessment measures for screening, clinical assessment, and outcome evaluation. The measures reviewed above represent a selected sample of the variety of instruments that have been developed to assess functional limitations in children. The WHO Disability Assessment Schedule has been revised in the form of WHO-DAS II to reflect the new content of the ICF (WHO, 2001), and has been used in studies with adult psychiatric populations. The WHO-DAS II however, does not purport to measure disability in children.

The development of measures specific to the ICF to assess disability in children should be guided by several considerations. A primary consideration is an approach consistent within a framework of children’s rights. Of equal importance is the translation of the biopsychosocial model of disability in the practices for children. Third, the goal for the development of measures should be to capture profiles of individual differences of children.

The publication of the UN Convention on the Rights of the Child in 1989 provided the ‘blue print for policy making on children’s issues’ (p. 243). Key principles underlying the convention include the child’s rights to be the first to receive services, to have their family protected, to have a family environment, to be protected from exploitation, and to receive education. While these principles are often implicit in policies and practice, the convention makes them explicit, constituting a universal bill of rights for the child.

Viewed within a framework of universal standards, the UN Convention on Rights for Children and the ICF complement each other. One defines the rights of children and the second provides the framework for documenting the dimensions for which those rights are to be carried out. These two universal documents are in turn complemented by with Rule 2 (#3) of the UN Standard Rules for the Equalization of Opportunities, indicating that a common level should serve as the basis for equalization of opportunity for children as for adults.

Implementing a biopsychosocial model of disability

The advancement of the biopsychosocial model of disability and recognition of the person–environment interaction is reflected in the broader perspective for
Applying international ICF to childhood disability

defining not just the health of individuals but that of groups and the role of environments. In such a view, a priority needs to be assigned to assessment of the proximal environments of home, school and community.

Arguing for primary paediatric care for children with disabilities, has emphasized the problems of defining childhood disability as well as obtaining reliable estimates. His emphasis on management of children with developmental manifestations of underlying health conditions is consistent with the ICF model. The biopsychosocial model of disability emphasizes that the needs of persons with disabilities are not just medical but more broadly, social, educational and functional in nature. In some instances it is important to recognize that medical treatments may be iatrogenic creating dependency and thereby creating further disability and secondary conditions.

Profiling individual differences

As individualization is central to the design and development of intervention plans for persons with disabilities, a key component of clinical assessment is measurement that can yield profiles of individual functional characteristics. The dimensions for measurement can incorporate basic neurophysiological processes as well as mental and behavioural functions. Such an application was described by Roux et al., in a study of 145 children with autism between 2 and 12 years of age. Ratings were obtained on four dimensions: intellectual impairment, language disorders, autistic behaviour and measures of electrophysiological activity. Multivariate analyses yielded five subgroups of children with distinct bio-clinical profiles reflecting different combinations of age, clinical indicators and electrophysiological data. An important application of the ICF is that it can contribute to the growing interest in identifying children on the basis of functional profiles rather than diagnostic labels. In this regard, various approaches have been described in which functional profiles of individual children or subgroups of children serve as the basis for identification. This approach is especially important in education, where categorical identification of students becomes barriers to intervention. For a child with specific instructional needs, knowledge about the child’s seeing function, language comprehension and learning ability are important. Regardless of labels such as mental retardation, deafness and cerebral palsy, all children need much the same carefully planned steps in learning how to read, write and solve problems.

Clinical description and documentation of changing functional status over time or with treatment is another purpose that needs to be considered in the development of measures based on the ICF. This type of application can be illustrated by a project of the American Academy of Pediatrics to develop measures of functional status to document outcomes of children with chronic conditions. Sullivan and Olson have described the process for developing such a measure for children with asthma. Seven domains were identified for measurement with items describing symptoms or functions rated on a 1–5 point scale. The domains encompassed the child’s physical symptoms and activity, the social activity of the child and family, the emotional impact on child and family and the utilization of health care. Completion of the scale by parents of 95 children between the ages of 5–12 years of age provided good reliability for five of the sub-scales. A useful step would be to examine the correspondence of the items with the ICF domains of body functions and structure, activities and participation. While many of the items in this scale were specific to the condition of asthma, others were generic and may be of value to consider in the development of measures based on the ICF for non-specific aspects of disability in children.

Central to the derivation of profiles of individual differences is comprehensive coverage of functional characteristics and behaviours of children. In this regard, Hack described the growing use of functional measures of health status and QOL measures. Hack has also stressed the importance of distinguishing between proximal neonatal impairments such as retinopathy of pre-maturity and distal impairments such as cerebral palsy. In this context, there is need for comprehensive measures of child characteristics and a core data set with specific reference to indicators defining the nature and severity of disability among children and youth with disabilities.

While the issue of comprehensive coverage of child characteristics it is important across all periods of childhood and adolescence, it is of particular concern in the first years of the child’s life. As we have noted elsewhere, references to the concepts of developmental delay, developmental morbidity and developmental vulnerability reflect recognition of the key role of early identification and early intervention to prevent further disablement. It is essential that the ICF provide coverage of characteristics and behaviours that are manifested in the early years. To this end, an examination of areas for such coverage in the ICF and associated measures is timely. Among areas of particular importance are those that reflect developmental progress in the early childhood years when change is particularly rapid. Representative candidates for expanded cov-
age of the ICF are described below and summarized in table 1. In a review of atypical behaviour in children under 36 months of age, Mindle has described several characteristics that may be useful to consider for inclusion as categories in the ICF version for children with implications for related measures. One of these relates to organization and regulation of behaviour. Significant variation in this characteristic may take the form of hypersensitivity to social or physical stimuli on the one hand and to hypo-sensitivity and under-reaction to stimuli on the other. A related characteristic is that of sensory modulation in children. At one end of the continuum, problems are manifested in sensory seeking behaviour in the form of excessive touching, increased activity and physical movement. At the other extreme, sensation avoiding behaviour is manifested in aggressive and or anticipatory behaviour in the form of somatic behaviours. These behaviours have been differentiated on the basis of dysfunctional modulation to tactile, vestibular and proprioceptive stimuli. Yet another aspect of problems of behaviour regulation is that of stereotyped and self-injurious behaviour. In a recent study of more than 450 young children under 40 months of age served in intervention programmes, Berkson, Tupa and Sherman found that 4.6% were characterized by stereotyped and self-injurious behaviours.

**Specific developmental issues**

Some characteristics of children are very important to document but represent a significant challenge to measure. Pain is a particular case in point in young children as well as children with severe disabilities. McGrath and colleagues have noted that pain is a common problem among children with severe cognitive limitations. Given the children’s difficulty of self-expression, parents are the most obvious and reliable source of information about the child’s experience of pain.

Sleep problems are often a source of concern in children’s development with significant variation of sleep in terms of duration, pattern or latency to fall asleep. Difficulties in going to sleep and staying asleep occur with some frequency in children with severe disabilities. In that sleep problems will have negative effects on the child as well as the family, documentation of the nature and severity of sleep problems is important to incorporate in the development of functional assessment measures. The fact that family factors may influence the establishment and maintenance of sleep problems of children reflects the interactive role of the caregiving environment on child development and disability.

Complementing the importance of documenting child characteristics and behaviour is documentation of the environment and its mediating role in disablement. Within the framework of child-environment interactions, Harkness and Super have advanced the concept of the ‘developmental niche’ to account for the influence of the environment on the health status of the child. To define the influence of the environmental factors, the developmental niche is characterized by three components. The first component encompasses the physical and social settings in which the child lives. Those settings include not only the natural and built environment but also the social and cultural practices that might exacerbate the effects of disease transmission. Customs of child care and child rearing constitute the second component. The third component is defined by the psychology of the care providers, that is, the values and beliefs that define parenting practices.

For many children with disabilities, a wide range of mechanical or technological devices facilitate the child’s physical functioning, mobility, communication and performance of personal tasks. Some children are dependent on technology, needing support of medical devices to compensate for impaired body functions. The fact that ‘... more systematic, comprehensive and causative data on technology dependent children are urgently required’ (p. 332) has implications for the use of the ICF to document characteristics of this low-incidence group.

**Table 1** Potential content areas for ICF for children and youth

<table>
<thead>
<tr>
<th>Body function</th>
<th>Body structures</th>
<th>Activities &amp; participation</th>
<th>Environmental factors</th>
<th>Qualifiers; inclusion/exclusion terms</th>
</tr>
</thead>
<tbody>
<tr>
<td>Sensory modulation</td>
<td>Wasting</td>
<td>Object and peer play;</td>
<td>Developmental niche;</td>
<td>Reduction of size; Delayed or precocious emergence</td>
</tr>
<tr>
<td>Behavioural regulation</td>
<td>Stunting</td>
<td>Pre-verbal communication;</td>
<td>physical and social settings, customs, psychology of</td>
<td></td>
</tr>
<tr>
<td>Self-injurious behaviour</td>
<td>Failure to thrive</td>
<td>Imitation;</td>
<td>caregivers</td>
<td></td>
</tr>
<tr>
<td>Stereotypes</td>
<td>Primary and secondary dentition</td>
<td>Caregiver-child interaction</td>
<td>Early motor activity</td>
<td></td>
</tr>
<tr>
<td>Sleep problems</td>
<td></td>
<td></td>
<td>Technology dependence</td>
<td></td>
</tr>
</tbody>
</table>
Measurement issues

Several issues can be identified related to measurement format in the application of the ICF. One of these is the challenge of assessing children who are limited in their ability to respond to measures or unable to convey information regarding their own experience. A related problem is the reliance on parents and caregivers as proxy responders for the child. As illustrated previously in the study by Sullivan and Olson, their measure relied on proxy reports of parents. An important priority is the development of measures that can directly capture the personal experiences and reports of children through interview or observation.

The utility of a restricted number of questions to identify children with severe disability has been examined in epidemiological as well as clinical studies. In the study by Fooks, infants who received fresh frozen plasma for intra-ventricular haemorrhage in the neonatal period were followed up at 2 years of age based on their assignment to four disability categories: (a) cerebral palsy; (b) developmental quotient two standard deviations below the mean; (c) blindness or reduced vision, and (d) hearing loss or using a hearing aid. A 29-item questionnaire was administered to clinicians in the study before the infants were 2 years of age. On the basis of that questionnaire, a reduced set of questions was identified that maximized the assignment of children to the four disability categories. Four questions were found to identify 56 of 61 children with severe disability and yielded a screening specificity value of 98.4%. The incidence of disability based on the four questions was 12.7% versus 12.2% based on evaluation by the clinician. In terms of domains of the ICF, three of the questions (motor; vision; hearing) are consistent with content of Body Function/Structures. The fourth question related to behaviour and seems consistent with the Activities domain. The findings of this study support the search for a limited set of indicators that can effectively identify children with disabilities. In concert with the content areas reviewed earlier, it is important that such indicators are developmental in nature.

Conclusion

The publication of the ICF followed that of the Convention on the Rights of the Child by more than a decade. If Convention principles are formalized in national laws and policies, the ICF holds promise as a means whereby the lived aspects of those rights can be documented. This means that in practice, the unique, developmental needs of children with impairments of function, activity limitations and restrictions of participation in community life should be documented and met through environmental accommodations and the provision of support. The issues reviewed in this paper have identified areas for consideration to enhance the use of the ICF in policy and practice with children. To that end, the ICF can serve as a universal standard to realize the rights of children with disabilities under the UN Convention on the Rights of the Child.

References


