

The ICIDH-2: Developments for a New Era of Outcomes Research

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This article reviews the important concepts that led to the development of the International Classification of Impairments, Disabilities, and Handicaps (ICIDH), explicates the International Classification of Functioning and Disability (ICIDH-2), and discusses implications of the ICIDH-2 as a conceptual framework for outcome measures. The original ICIDH opened the door to include factors outside the traditional classification boundaries of disease, illness, and functional limitations that have framed the concept of disability. The new factors in the ICIDH-2 include a dimension for participation in social activities and a listing of environmental factors that are important for understanding the complexity of disability. The ICIDH-2 offers an opportunity for building a consensus on the terms used to describe disability and on the scope of factors to include in studying disability.

Key Words: Disabled persons; Outcome assessment (health care); Rehabilitation.

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THIS ARTICLE REVIEWS the development of the International Classification of Impairments, Disabilities, and Handicaps (ICIDH), describes the conceptual problems with the ICIDH that led to its revision (International Classification of Functioning and Disability [ICIDH-2]), outlines the revision process, explicates the ICIDH-2, and discusses the implications of the ICIDH-2 as a conceptual framework for outcome measures.

INTERNATIONAL CLASSIFICATION OF IMPAIRMENTS, DISABILITIES, AND HANDICAPS

Background

The ICIDH is among the “family of classifications” developed, maintained, and disseminated by the World Health Or-

ganization (WHO).¹ Another member of this family is the much older and more widely used International Classification of Diseases (ICD). It was first published in 1893 and is now in its 10th revision; the ICIDH was first published in 1980 and is now undergoing its first revision. In evaluating the progress of the ICIDH to date, it is well to keep in mind the long and difficult history of its older sibling. Creating and maintaining a successful international standard for health-related classification is, by its nature, a difficult and never-ending process.

The ICIDH was conceived as a response to the problem of evaluating the effectiveness of health care processes. Health care processes involve contact by a patient with the health care system, a response by the system, and an outcome of that response. A full evaluation requires measuring each part of the process; but a particular problem exists with respect to measuring outcomes. When acute diseases predominated, measuring outcomes was relatively straightforward: the disease was present or not; if present, it ran its course, the patient was cured or died. The ICD evolved under that health paradigm, and is useful for classifying existing conditions (morbidity) or causes of death (mortality).

With the elimination or control of many acute diseases, however, chronic disease, disorders, and impairments became the major concerns of the health care process. Measuring health outcomes for these conditions is more problematic, because neither cure nor death is a likely outcome. The medical model of progression from etiology, to pathology, to manifestation, to diagnosed condition is not useful in describing outcomes for persons whose conditions persist over long periods of time. For them, a model is needed that goes beyond diagnosed conditions to describe the *consequences* of those conditions. The ICIDH was developed to meet that need, which is reflected in its subtitle, “A manual of classification relating to the consequences of disease.” The developers of the ICIDH believed that if it were used in conjunction with the ICD, the full range of phenomena relevant to evaluating the outcomes of health care responses could be described. The ICIDH was designed to accommodate and foster the measures of disability outcomes that are the focus of this supplement.

The authors of the ICIDH envisioned 3 uses for the classification: for statistics on the consequences of disease, for statistics on use of health services, and for filing and retrieving case records according to categories in the classification. Furthermore, they foresaw applications of the classification in several professional fields, including medicine, rehabilitation, and social welfare. The stated goals of the ICIDH were modest: “It seeks to contribute to the promotion of uniformity in broad concepts and terminology and, by indicating ways in which individual attributes may be grouped together for simplification, to encourage standardization and an improvement in the comparability of data.”² The authors expected and invited criticism of the manual. The manual is regarded as innovative but inadequately tested, an opinion reflected in WHO’s notation on the title page: released “for trial purposes.”

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Theoretical Framework

In the ICIDH, WHO proposed that the medical model

Etiology → Pathology → Manifestation

be extended by a new model

Disease/disorder → Impairment

→ Disability → Handicap

that would include the consequences of diseases common to chronic conditions, disorders, and impairments.

The arrows shown in the models were intended to show a *typical* causal pattern, not a *necessary* causal pattern; though the different consequences of disease or disorder typically progress in the order shown, in particular cases any of the progressions may be reversed, arrested, or omitted.

Each term in the model refers to a different “plane of experience” of the consequences of disease, and for each plane there is a corresponding classification, described as follows: (1) *Impairments* (I code), concerned with abnormalities of body structure and appearance and with organ or system function, resulting from any cause; in principle, impairments represent disturbances at the organ level.¹ (2) *Disabilities* (D code), reflecting the consequences of impairment in terms of functional performance and activity by the individual; disabilities thus represent disturbances at the level of the person.¹ (3) *Handicaps* (H code), concerned with the disadvantages experienced by the individual as a result of impairments and disabilities; handicaps thus reflect interaction with and adaptation to the individual’s surroundings.¹

The 3 classifications are conceptually distinct. Impairment refers to consequences of disease or injury as experienced by the body, disability to disease consequences as experienced by the person, and handicap to disease consequences as experienced in person-environment circumstances. In an application of a classification, a user would need to decide which classifications are appropriate—the ICD, Impairments, Disabilities, or Handicaps. Because the classifications have different purposes, it is possible that a datum can be classified in more than 1 classification. For instance, “unable to see” could be coded to ICD-9 code 369, to Impairment code 51, or to Disability code 26.

Which classification should be used? It depends on the larger purpose of the classification. If it is to understand the cause of conditions, the ICD should be chosen because it allows for a specification of blindness with respect to its causes. If the purpose is to assess the need for low vision services, Impairments should be chosen because it facilitates the grouping of low vision impairments. If the purpose is to plan a course of rehabilitation, Disabilities should be used because it provides a means for specifying the outlook or prognosis of a disability.

The ICIDH shares many of its taxonomic properties of the ICD. The Impairment classification is most like the ICD in that it is hierarchical, exhaustive, and classifies entities as being either present or absent. The Disability classification, like the ICD and Impairment, is also hierarchical and exhaustive. However, it deviates from the threshold principle (all or none) by allowing an optional severity scale, indicated by the addition of a 4th digit to the usual 3-digit Disability code. With respect to taxonomic principles, the Handicap classification is, in the opinion of the ICIDH authors, “radically different” from the ICD, Impairments, and Disabilities: it is *not* hierarchical; it is *not* exhaustive; it does *not* use the threshold principle; and its categories are *not* mutually exclusive. Moreover, the entities it

classifies are *not* conceived to be unitary phenomena (ie, diseases, impairments, disabilities), but interactive phenomena.

As the authors stress, the taxonomic peculiarity of the Handicap classification reflects the primitive level of the Handicap concept. The authors wanted to distinguish between what people *could* do independently of environmental factors (Disability), and what they actually *do* do when situated in an environment (Handicap). In their discussion of Disabilities, they write:

The key influence in designing this classification has been the feasibility of recording the interface between the individual and his environment in such a way as to display his *potential*; this may be supplemented by the handicap classification as a means of indicating the extent to which potential is *realized*.¹ (emphasis added)

The distinction is meant to clarify and emphasize the independent causal role of environmental factors in determining what is actually performed, in real-life situations, by persons with impairments or disabilities, as opposed to what they might be capable of performing if the environment were controlled, standardized, or neutralized.

A full classification of Handicap as thus conceived would be voluminous and complex, because it would have to encompass the whole range of person-environment circumstances. The authors limited the scope of the classification in several ways. First, they limited the range of circumstances to performance of social roles. In effect, the environment of interest is limited to the expectations people have of behavior by other people of a particular age, gender, and social position, within a particular culture. Second, they further limited the scope of the classification to “*survival* roles,” as defined in Maslow’s hierarchy of needs.³ The Handicap classification comprises 6 dimensions (survivor roles) and a 7th dimension for “other roles.” Third, they limited the scope of the classification to “disadvantage” in performance of survival roles, where disadvantage is defined as socially perceived failure to conform to expected role behaviors, either by deficit or excess behavior.

Limitations and Changes

As noted, the ICIDH was published in 1980 “for trial purposes.” Disability specialists from several countries met periodically thereafter, under the auspices of WHO, to review the classification. In 1992, it was decided that the ICIDH had some shortcomings that should be corrected. When the ICIDH was reprinted in 1993, it included a Foreword that listed some of the shortcomings and announced WHO’s intention to initiate an international effort to revise the classification. There were several general shortcomings and a longer list of specific problems that were to be addressed in the revision. The general shortcomings included (1) insufficient attention to the role of the environment; (2) overlap between the Impairment and Disability dimensions, and between the Disability and Handicap dimensions; and (3) a lack of clarity about the causal and temporal relationships among the 3 dimensions.³⁻⁹

INTERNATIONAL CLASSIFICATION OF DISABILITY AND FUNCTIONING

Purposes, Organization, and Activities of the Revision Process

The general revision of the ICIDH was undertaken by WHO collaborating centers for health classifications. Collaborating centers are organizations in WHO member nations that have entered into an agreement (“terms of reference”) with a WHO office to collaborate on specified activities. Collaborating cen-

ters usually are responsible for WHO activities in geographic areas defined by national boundaries and language. Thus, the WHO Collaborating Center for the Classification of Diseases in North America includes English-speaking North America (ie, United States, Canada).

Among the scores of WHO collaborating centers are a dozen or so that focus on health-related classifications. Some of those focus specifically on the ICIDH, whereas others include the ICIDH, the ICD, and other classifications in the WHO “family of health-related classifications.” Three collaborating centers were represented at the 1992 meeting: the Netherlands, France, and North America. To begin revision, each of those centers took responsibility for 1 dimension of the ICIDH, based on previous experience and interests. The lead for Impairments was taken by France, for Disabilities by the Netherlands, and for Handicaps by North America.

It was also recognized that some issues cross-cut the existing dimensions and needed ongoing attention in the revision. WHO invited specialists with interests in those issues to propose formation of issue-oriented “task forces” with their own resources, international representation, and work plans. WHO approved 3 such proposals for International Task Forces on Children, the Environment, and “mental” disability (designated Alcohol, Behavioral, Mental, Cognitive, and Developmental Disabilities).

The centers and task forces did the revision. The membership of these bodies was broad based, including people with disabilities (eg, executive director of Disabled People International, disability issue-thought leaders, social scientists), epidemiologists, health care professionals, scientists, government officials, and administrators. Annual international meetings were held to review progress reports, debate and decide issues, and plan work for the following year. In the periods between international meetings, some centers, including the North American Center, held their own annual revision meetings.

A major milestone in the revision process was achieved with the release of the “Alpha Version” of ICIDH-2 in May 1996. The Alpha version was circulated widely for comments. WHO then produced a new Beta-1 draft in April 1997. From June 1997 through December 1998, the English draft was translated into other languages and tested by using several protocols developed by WHO, which collected and analyzed the test information. A new draft, Beta-2 was produced by WHO in August 1999 for additional testing, with a focus on test coding of information on actual patients or WHO-developed standard case studies.

Current Status and Future Plans

Testing of the Beta-2 concluded in September 2000, and a new draft is being prepared by WHO for review and approval. Important developments in the Beta-2 draft were the inclusion of Environment Factors as a recognized dimension of disability, new nomenclature for the dimensions, and a proposed new title for the classification: International Classification of Functioning and Disability. The final version of the new classification is scheduled for presentation to the World Health Assembly (WHO’s governing body) for review and approval in May 2001.

Description of the ICIDH-2

To address the deficiencies in the ICIDH, a new classification has been developed that includes environmental factors, addresses dimensional overlaps, and proposes associations between dimensions.⁹ A major goal of the ICIDH-2 is to establish a common language for describing functional states associated with health conditions and to improve communications among

health care workers, other sectors, and people with disabilities. In addition, the revised ICIDH-2 attempts to use neutral terminology; to form a systematic coding scheme for use across health information systems; to provide a scientific basis for the impact of health conditions on life situations; to stimulate better care and services to improve the participation in society of people with disabilities; and to permit comparisons of data across countries, health care disciplines, social services, and over time.

The 3 components of the 1980 ICIDH were impairments, disabilities, and handicaps. The model proposed in the ICIDH-2 includes both positive and negative aspects of dimensions, but the coding scheme used in the ICIDH-2 allows only for coding of the negative.¹⁰ The positive aspects (functioning) are described as dimensions of body structures and functions, activity, and participation (see fig 1, table 1).

For the coding scheme used in the ICIDH-2, the negative aspects (disability) of each of these dimensions are described as impairment, activity limitation, and participation restriction. The negative aspects of disability are coded in terms of a uniform qualifier for the extent or magnitude of the impairment, limitation, or restriction (see table 1). The uniform qualifier refers to the extent or magnitude of the impairment limitation, or restriction as none (0), mild (1), moderate (2), severe (3), or complete (4). The scope and qualifiers of each dimension of the ICIDH-2 are described in more detail in the following subsections.

Body structures and functions. Significant deviations or loss in body structures and functions are described as impairments. Impairments of function include mental, sensory, speech, and voice as well as the cardiovascular, hematologic, immunologic, and respiratory; digestive, metabolic, and endocrine; genitourinary and reproductive; neuromuscular and movement; and skin. Body structures are classified into major categories of nervous system; eye, ear, and related structures; voice and speech; cardiovascular, immunologic, and respiratory; digestive, metabolic, and endocrine systems; genitourinary system; movement- and skin-related structures. Both body functions and structures are coded by using the uniform qualifier. A second qualifier is under development that will be used

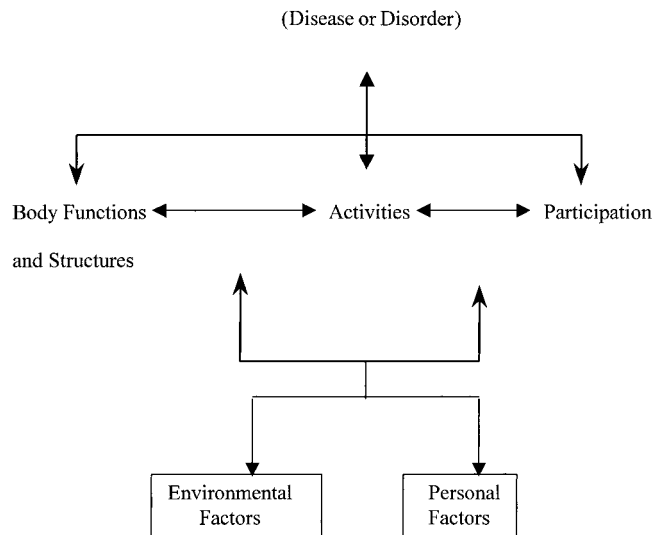


Fig. 1. Current understanding of interactions between the dimensions of ICIDH-2. Reprinted with permission of the World Health Organization.¹⁰ All rights reserved.

Table 1: Current Understanding of Interactions Between the Dimensions of ICIDH-2

	Body Functions and Structures	Activities	Participation	Contextual Factors
Level of functioning	Body (body parts)	Individual (person as a whole)	Society (life situations)	Environmental factors (external influences on functioning) + personal factors (internal influences on functioning)
Characteristics	Body function Body structure	Performance of individual's activities	Involvement in life situations	Features of the physical, social, attitudinal world + attributes of the person
Positive aspect (functioning)	Functional and structural integrity	Activity	Participation	Facilitators
Negative aspect (disability)	Impairment	Activity limitation	Participation restriction	Barriers and hindrances
Qualifier				
First			Uniform qualifier: extent or magnitude	
Second	Localization	Assistance	Subjective satisfaction (under development)	(under development)

From ICIDH-2: International Classification of Functioning and Disability. Beta-2 draft, short version. Geneva: World Health Organization; 1999. p 15. Reprinted with permission.¹⁰ All rights reserved.

to indicate duration, growth, and development of the body functions. An example of coding body structures and functions by using the ICIDH-2 is the classification of a severed spinal cord under Chapter 7 (Structure Related to Movement) as a structural impairment (s120.4) and an inability to control voluntary movements of the lower limbs under Chapter 7 (Neuromusculoskeletal and Movement Related Functions) as a functional impairment (b760.4).

Activities. Activities are performance of person-level tasks or activities undertaken by the person. The domains of activity are: learning and applying knowledge; communication; movement, moving around, self-care, domestic, interpersonal; and performing the simple to complex tasks involved in major life activities. Activities are the observable and reportable performance of the actions of individuals in the context of their culture. They are not the results of controlled tests of capacity or aptitude to perform specified activities. Nor are they the potential of what the person might be able to do. Activity limitations are classified to the extent that the individual has difficulty performing the activity. An important consideration to activity performance classification is taking into account whether the individual uses a device or personal assistance in performing the action. When classifying activities, the activity type is coded within an activity domain, given a qualifier for level of difficulty, and assigned a qualifier for level of assistance used (none = 0, nonpersonal = 1, personal = 2, both nonpersonal and personal assistance = 3, unknown level of assistance = 9). For example, inability to walk and use of a wheelchair for mobility would be classified as follows: Activities dimension (a), Chapter 4 (Activities of Moving Around) under the level 2 heading of "walking activities" (410), level of difficulty qualifier (4), and assistance qualifier (1) for a resulting code of a410.41. Qualifying activity limitations in performance with assistance is an addition to the activity dimension that is being considered to provide a method of establishing the degree of mitigating influence assistance has on the severity of activity limitation.

Participation. Participation is defined as "an individual's involvement in life situations in relation to health conditions, body functions and structures, activities and contextual factors."¹⁰ A key term in this definition is involvement. The

authors of the ICIDH-2 state that involvement means inclusion of the individual in life activities in the context of where they live. The restriction of participation or involvement in life activities by external factors (social rules) is referred to as participation limitation/restriction. Much like the earlier concept of handicap, participation restriction is assessed by comparing the participation in life activity of persons with and without disability in that society. The classification of participation restriction is made by placing the observed involvement in a life activity in 1 of the 9 participation domains that include: personal maintenance; mobility; exchange of information; social relationships; home life and assistance to others; education; work and employment; economic life; and community, social, and civic life. Participation is qualified by the degree of restriction experienced. For example, if mobility outside the home is moderately restricted as a function of the lack of the availability of accessible mass transit, then the participation code (p) would be assigned as follows: Chapter 2 (Participation in Mobility) under the second level heading (230) titled "Participation in mobility outside the home and other buildings" and restriction qualifier of moderate (2) resulting in the full code of p230.2.

Contextual factors: environmental and personal. Environmental factors include the physical, social, and attitudinal environments that influence individual functioning. Environmental factors are organized into 6 chapters that include products and technology; natural environments and man-made changes to the environment; support and relationships; attitudes values and beliefs; services; and systems and policies. The facilitating or inhibiting value of the environmental factors is noted as a barrier (no = -0, mild = -1, moderate = -2, severe = -3, complete = -4) or facilitator (no = +0, mild = +1, moderate = +2, severe = +3, complete = +4). The availability of a wheelchair for personal mobility use indoors and outdoors would be coded as an environmental factor (e) as follows: 140 for the Chapter 1 (Products and Technology) second level heading "Products for personal mobility and transportation" and as a severe facilitator resulting in a code of e140.+3.

Personal factors are described as "gender, age, other health conditions, fitness, lifestyle, habits, upbringing, coping styles,

social background, education, profession, past and current experience (past life events and concurrent events), overall behaviors pattern and character style, individual psychological assets, and other characteristics, all or any of which may play a role in disability at any level."¹⁰ Although personal factors are included in the ICIDH-2 model, they are not classified because "of the large social and cultural variance associated with them."¹⁰ Assessing personal factors and using them in conjunction with the ICIDH-2 will be the responsibility of the person(s) conducting the classification and assessment.

DISCUSSION

The ICIDH-2 addresses several inadequacies of the original ICIDH by introducing the dimensions of Activity, Participation, and Contextual Factors. These dimensions provide a classification system that reaches beyond traditional body-centered descriptors of disability to include factors that social and empowerment models of disability advocate as being important to understanding disability.¹¹⁻¹³ In addition to changes in the ICIDH-2 dimensions, new approaches to coding are being considered. The addition of the second qualifier to the Activity dimension—use of assistance—will provide a systematic method for classifying performance in context of support used to perform an activity. Adding a second-level qualifier of subjective satisfaction to the Participation dimension may provide people with disabilities an opportunity to contribute evaluative comments on their participation in major life activities. Categories and qualifiers for the Contextual Factors of environmental facilitators and barriers are under development (table 1).¹⁰

However, more work is necessary to clarify the concepts, definitions, and coding schemes. If the distinctions are not made explicit, then use of ICIDH-2 might be limited. Linking the existing rich set of measures of health, function, and quality of life with emerging measures of participation and environment is a challenge that needs to be addressed. Some work has addressed these issues and may provide direction for future development of the ICIDH-2. Fougereyrollas^{8,14} proposed that the Activity-Participation distinction be made by using the capacity to perform as the basis for the Activity dimension while defining Participation as the performance of major life activities in uncontrolled environments. Comparing the relative involvement of people with disabilities to those without disabilities as an index of Participation has been suggested by Whiteneck et al¹⁵ and Dijkers et al.¹⁶ Tools to assess participation by children with disabilities in school settings are being developed by Lollar et al.¹⁷ Gray et al (unpublished observations) have developed a survey of participation for mobility-limited individuals that includes subjective evaluation of importance, choice, and satisfaction in participation. WHO is testing a measure (World Health Organization Disability Assessment Schedule II) that has 5 domains (understanding and communicating, getting around, self-care, getting along with others, household and work) in the Activity dimension of the ICIDH-2 and 1 domain "participation in society" in the Participation dimension of the ICIDH-2.¹⁸

Nearly all critics of the original version of ICIDH agree that including environmental factors in the revised ICIDH-2 was necessary. However, just how environmental factors are to be integrated into the classification scheme remains unresolved. Fougereyrollas et al¹⁴ developed the Environmental Quality Assessment Scale to select environmental factors that need to be removed (barriers) or that need to be added (facilitators) for full participation. Whiteneck et al¹⁵ are developing a short survey instrument (Craig Hospital Inventory of Environmental Factors) to assess the magnitude and frequency of environmental

factors that are a problem to full participation (barriers) for both people with and without disabilities. School environments have been surveyed by Simeonsson et al (unpublished observations) with regard to the influence they might have on the participation by children in school activities. Gray et al (unpublished observations) have developed a self-report survey, Facilitators and Barriers Survey for mobility-limited individuals, that addresses both environmental barriers and facilitators to participation in home, community, and work settings.

CONCLUSION

The original ICIDH broadened the concept of disability by including factors outside the traditional classification boundaries of disease, illness, and functional limitations. The ICIDH-2 is responsive to the evolution of disability models that now include environmental factors as important contributors to understanding the complexity of sources for disability. This inclusiveness offers an opportunity for a consensus on the terms used to describe disability and on the scope of factors to include in studying disability.

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