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# *Cross-Cultural Applicability Research on Disablement: Models and Methods for the Revision of an International Classification*

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The World Health Organization (WHO) has undertaken the revision of the International Classification of Impairments, Disabilities and Handicaps (ICIDH), originally adopted by the World Health Assembly in 1980. The existing classification has been criticized for not meeting the modern standards of cross-cultural applicability necessary for an international classification. A field-based empirical test of a revised version of the ICIDH was conducted in 17 centers in 15 nations, following extensive discussions among WHO collaborating centers, advocacy groups, representatives of disabilities organizations, governmental health programs, consultants, researchers, and WHO staff. The ICIDH Cross-Cultural Applicability Study utilized a suite of 6 ethnographic and statistical methods chosen to test 12 different aspects of the cross-cultural validity of the classification system and the revision process. The selected methods include: 1) descriptive narratives about disablements in the local culture; 2) translation and language analysis protocols; 3) pile sorting; 4) concept mapping; 5) key informant interviews with ranking exercises; and 6) focus groups. The data produced by these methods were found to be extremely valuable in revising the ICIDH classification and in developing disability-assessment instruments linked to the ICIDH.

**Key words:** disabilities, handicap, impairments, international classification, ethnographic methods, ICIDH-2

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**T**he World Health Organization (WHO) is responsible for the development, maintenance, and revision of international health classifications. The ICD (International Classification of Disease and Related Health Problems) is the most widely used WHO classification. By treaty, it is used throughout most the world to identify and report morbidity and mortality statistics, improve health care policy, and provide a basis for research and communication about medical conditions. ICD is currently in its tenth version (ICD-10).

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The International Classification of Impairments, Disabilities, and Handicaps (ICIDH) was developed within the family of WHO classifications to complement the ICD. The ICIDH was first adopted by the World Health Assembly in 1980 (WHO 1980). It is divided into three related, but stand-alone, sections on "impairments," "disabilities," and "handicaps." The impairment section of the classification identifies body-level functional and structural problems (e.g., loss of a limb; difficulties in concentration). The disability section identifies problems at the whole-person level of activity (being unable to climb stairs; having difficulty reading). The handicap section describes hindrances to participation in society caused by conditions that are external to the individual (e.g., not being allowed to drive or vote due to a mental health

condition; not having access to stores due to physical barriers for people in wheelchairs).

ICIDH-1980 was intended for worldwide use but failed to achieve that level of acceptance. It is currently in use in several European countries, North America, and Japan (Bichenbach et al. 1999; deKleijn et al. 1989; Ustun et al. 1995). It is not in use in most third world countries, where adoption has been hampered by significant issues of cross-cultural applicability.

Consumer advocacy organizations have attacked the classification based on the perception that it predominantly focuses on negative individual conditions rather than potential positive functioning. They emphasize that this aspect of the classification can be used to stigmatize disabled persons. The classification also describes social participation or handicap as a consequence of individual disease but fails to identify social conditions that cause external restrictions for individuals, causing a potential "blaming the victim" problem for parts of the classification.

WHO collaborating centers have contended that the model of disablements used to create the original classification is obsolete. It does not fit current understanding of the conditions that influence the disablement process (e.g., Dickson 1997; Halbertsma 1996). They and others have notified WHO of missing elements in the classification caused by changes in the overall view of disabilities through time. Some of these constituencies feel an expanded understanding of environmental factors and universal design principles needs to be incorporated in the revised version of the classification (e.g., Fougeyrollas 1995), while others focus on different parts of the classification (Halbertsma 1996). A number of groups have noted that the classification was not useful because it did not have assessment instruments that were closely tied to the classification.

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WHO responded to these critiques by initiating a formal revision of ICIDH. The revision process involves four constituencies. These include representatives from 1) the three existing WHO ICIDH collaborating centers<sup>1</sup>; 2) at least 20 worldwide field trial centers, 3) three international task forces<sup>2</sup>; and 4) a number of consumer advocacy organizations. WHO headquarters staff in the Mental Health Division are providing technical support for the revision, assisted by a core of methodological and content-area WHO consultants.

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The revision process was initiated with considerable discussion and planning. Initial revisions were produced by the WHO ICIDH collaborating centers. International meetings were held, and the strengths and weaknesses of the proposed revisions were thoroughly discussed by representatives of disablement advocacy groups, collaborating center representatives, WHO staff and consultants, and task force representatives. In 1997 the recommendations were accepted as a draft version of the ICIDH, with the proviso that these elements be further refined and field tested. The draft revision version was labeled the Beta 1 Draft of ICIDH-2.

Highlights of the initial theory or model-level changes from the 1980 ICIDH include: 1) changing the model used

to describe the relationships among the parts of the ICIDH from a linear, virtually causal model, to a multiplex one; 2) renaming and redefining the three sections from Impairments, Disabilities, and Handicaps to Impairments, Activities, and Participation, to better describe the elements of the classification and to create a neutral description of the elements; and 3) providing the overall umbrella term of "functioning and disablement" to describe the universe of the classification. The empirical and pragmatic changes made at the single-item classification level include adding operational definitions to each element in the classification, adding missing items, and devising a systematic coding or numbering system for the classification.

One stage of the revision process included the initiation of a Cross-Cultural Applicability Research Study (ICIDH CAR) conducted by WHO to assist the ICIDH revision process and to help develop ICIDH-linked disablement assessment instruments. The study addressed two important questions. Is the disablement construct (the proposed ICIDH model of disabilities) culturally relevant at a global level? Can both the cultural and the psychometric requirements for the development of disabilities instruments be accommodated? Data were collected during a series of field trials of the ICIDH-2 and from the ICIDH CAR study. Both data sets were designed to produce an empirical, cross-culturally competent revision of the classification and psychometrically stable instruments that collect cross-culturally comparable data. The disablement-assessment instruments will be used to produce international statistics and help plan local, regional, and global health services and policy. This report focuses on the methodology used in the ICIDH CAR research trials and provides examples of how the CAR data were used in revising the classification.

### A Model for Cross-Cultural Applicability Research on International Classifications

Revising an international classification like the ICIDH presents a number of challenges. The classification must be based on some natural or consensual framework that makes it useful for multiple purposes (e.g., policy development, health communications, epidemiological research, third-party payment systems). It must accommodate significant differences between cultures based on language, belief, environmental conditions, and values. It must be capable of being successfully translated into each local language with perfect or near perfect correspondence of all items. It must contain concepts that are found in or can be explained in the local culture. It must be useful to the local culture. And it must allow correct comparisons of conditions in the local culture with conditions in all other cultures. These requirements dictate that the ICIDH classification of disablements must be conceived in a common way in very different settings. The cross-cultural methods presented in this article were selected to allow these assumptions to be empirically tested.

Prior to the field studies, baseline data were collected on current international legislation, disability research instruments and items, and general disablements information. A pilot study was also conducted to pretest the proposed methods in six sites in four countries. Some of these methods have been used in cross-cultural research done by WHO in other projects related to mental health, substance abuse, and quality of life (WHO 1994; WHOQOL Group 1995; Room et al. 1996). However, several of the methods have not been used previously on this scale or for this purpose. The pilot test was successful and allowed an interim refinement of the classification system, eliminating some linguistic problems and improving the operational definitions for many items prior to the field test of the Beta 1 draft.

The ICIDH CAR study was designed to satisfy 12 data needs in relation to both the ICIDH revision process and instrument development: 1) identify linguistic equivalencies for conceptual transfer of elements of the classification into local languages and back to English; 2) explore the cultural contexts, practices, and values concerning disablements in the local culture; 3) investigate whether the proposed structure of the classification has good cross-cultural stability; 4) conduct an item-by-item evaluation of the cross-cultural applicability of each facet of the classification; 5) explore alternative models for the classification; 6) collect data on the parity or lack of parity in accommodation and level of stigma between mental health and physical disablements; 7) collect data on the boundaries between the three levels of the classification system; 8) establish information on the thresholds that apply to disablements (when someone is considered disabled and when are they not shows significant cultural variability); 9) investigate information on stigma attached to various types of disablements; 10) produce a description of the current programs and need for programs that serves populations with disabilities; 11) compare the relative importance of different types of disabling conditions in different cultures; and 12) create a general description of the place and meaning of disabilities and disability programs in local cultures.

The practical aspects of the design required conducting the research at a number of different centers around the world that have varying levels of experience with qualitative and quantitative research methods. The methods had to be easy to use, inexpensive, comprehensive, and capable of producing defensible results. Table 1 presents the matches between the specific methods that were chosen and the 12 identified revision needs. It should be noted that the selected methods not only cover the needs, but they also allow significant amounts of triangulation of results without unnecessary duplication.

The ICIDH CAR model was also designed to address a consistent issue for multisite cross-cultural research. The research requires a standardized sampling framework that does not place an extreme burden on the various centers. We used qualitative sampling procedures for the bulk of the CAR study, except in those cases where statistical power needs dictated a quantitative sampling approach. The ethnographic sampling

framework was comprised of selected individuals who were especially knowledgeable about their culture, rather than randomly selected individuals who might not be able to contribute substantively to the study (cf. Trotter and Schensul 1999; see Johnson 1990). The process appropriately differs from probabilistic (forms of random) sampling due to the goals of the study, especially the need to interview individuals who are cultural experts and who have substantive knowledge in the area of disablement.

The ICICH CAR research was conducted at 19 centers in a total of 15 nations.<sup>3</sup> Thirteen centers completed five of the research tasks, excluding the focus groups, and seven centers conducted the focus group data collection in addition to the other tasks. Table 2 describes the number of informants represented in the individual data sets or the total data collection efforts for other methods.

## ICIDH CAR Methods and Data Summaries

The following sections provide details on the methods used, the types and the ranges of data collected, as well as examples of the impact of the data on the ICIDH revision and the progress of the assessment-instrument development program.

### Center Description Narratives

Each center responded to a series of qualitative questions about local cultural knowledge, beliefs, and cultural values about disablements. The center questionnaire was divided into three sections. Section 1 requested information about the general local cultural views of disablements. It explored the existence of general disablement terms. It also described the presence or absence of parity between physical and mental disablements in law, benefits, insurance, health services, and public opinion. It requested the center to identify advocacy and charitable organizations that deal with disablements, and it asked about the stigma attached to common conditions associated with disablements. Section 2 of the center description questionnaire asked for information on disability compensation and support systems in the culture. It requested information on benefits and health coverage from federal, regional, and local authorities. It also explored the processes used to identify and establish the level of disability that is compensated or covered by law for various disabilities. The final section explored the general rehabilitation system present in the society. It also elicited information on the available workers' compensation system and the system of support for current and former military personnel. Each center submitted a comprehensive report describing the context of disablement in its culture.

The center reports identified key similarities and differences in the cultural views of disability conditions across nations. They confirmed that the concept of disabilities exists in the languages and cultures of all of the participating centers. Each of these societies provides some arrangements

**Table 1. The ICIDH CAR Model: Matching Methods with Data Needs**

Research Methods (Type[s] of Data Collected)	Research Issues for Project	12 Data Needs by Method
Center description information (qualitative)	Current practices and needs for disability services; policy information on disablements; values and cultural responses to disablements; legal status of disablement assistance	1) linguistic equivalencies; 2) cultural contexts, practices, and values concerning disablements; 5) exploring alternative models; 6) parity or lack of parity; 10) description of the current programs; 12) a general description of the meaning of disabilities
Translation/back-translation and linguistic analysis protocols (qualitative)	Linguistic equivalencies for items or sections of the classification; identification of problematic individual items	1) identifying linguistic equivalencies for conceptual transfer; 12) a general description of the meaning of disabilities. <span style="float: right;">A</span>
Pile sorting (qualitative and quantitative)	Cross-cultural stability of the classification; identification of problematic individual items; discovery of underlying cultural dimensions within the classification system	3) investigating the proposed structure of the classification; 4) item-by-item evaluation of the cross-cultural applicability
Concept mapping (quantitative, some qualitative)	Cultural applicability of items; problems with taboo; age and gender bias; socioeconomic conditions; and linguistic problems with items	2) cultural contexts, practices, and values concerning disablements; 3) the proposed structure of the classification; 4) item-by-item evaluation of the cross-cultural applicability, 7) data on the boundaries of the classification system
Key informant interviews (Qualitative, ranking, quantitative)	Cultural contexts, practices and values relating to disablements; perceived relative severity of different disabling conditions; comparison between different disabling conditions	2) cultural contexts, practices and values concerning disablements; 6) parity or lack of parity; 8) thresholds of disablements; 9) stigma attached to various types of disablements; 11) relative importance of different types of disabling conditions in different cultures
Focus group (Qualitative)	The conceptual integrity of ICIDH model and suggestions for modifications; exploration of current practices and needs; parity between mental, physical, and drug- and alcohol-related disablements	5) exploring alternative models; 6) parity or lack of parity; 7) the boundaries between the three levels; 8) thresholds of disablements; 9) information on stigma attached to various disablements; 10) a description of the current programs and needs; 11) relative importance of different types of disabling conditions; 12) a general description of disabilities

to support and to improve the social participation of disabled persons. Often these arrangements are situated within the family, or accomplished by means of informal accommodations within the community, but all of them form a cultural response to disabilities (Ingstad and Whyte 1995).

As resources and cultural values allow, societies have set up systems of societal assistance or support for disabled individuals. Such systems often target a specific disability, such as blindness, or they may deal with disabilities much more broadly defined. In some societies, provisions for disabilities

**Table 2. Number of Informants or Data Collection and Reporting Sessions**

Method	Total N (All Centers)
Center descriptive narrative	14 (Tunisia and Egypt combined)
Translation and linguistic analysis	12 (3 used original English version)
Pile sorting	450 informants in 19 centers
Concept mapping	416 informants in 18 centers
Key informant interviews	230 informants in 18 centers
Focus groups	22 focus groups in 7 centers

are incorporated into a wider social benefit program. Distinctions are often made between disabling conditions in terms of the kind or amount of resources available to the disabled. These distinctions often reflect differences in cultural values concerning the worthiness or stigma of those with the disability as well as the circumstances in which the disability arose. For instance, a military veteran with a war-related injury may receive more assistance than an individual with an identical disability that resulted from a sport-related accident. Those with physical disabilities may receive greater assistance than those with mental disabilities or with disabilities linked to drinking or drug use. Diversity in the society and in the political and social service systems may mean substantial variation in handling disabling conditions.

### Translation/Back-Translation and Linguistic Analysis Protocol

A pilot study was conducted prior to the full ICDH CAR field research program. Four centers were asked to do a complete translation/back-translation protocol for the entire ICDH classification<sup>4</sup> and were asked to complete a pile sort trail on the key concepts in the classification. The translation was conducted by professional translators familiar with the ICDH. The back-translation was conducted by translators who were not familiar with the ICDH and who had not seen the English version. Each item that was back-translated differently from the original was identified, recorded, and discussed. The translation team made recommendations for reconciliation of differences, even if the translation used a very close English synonym. The pilot process determined that the majority of the ICDH did not show significant cultural divergence, even between very different language groups. However, the pilot study did identify two areas where problems consistently occurred in the classification. First, the new introduction and the changes in the conceptual model for the classification had not gone through an intensive editing process during their development. This caused a certain amount of ambiguity in the original English version that resulted in confusion in the translated version. Second, there were a number of terms and phrases in the classification that were consistently problematic across sites and languages. The pilot linguistic data were combined with pilot pile sort data, producing two lists of items that needed further exploration in the full ICDH CAR study. One was a list of concepts and phrases at the conceptual level of the classification, and the other was a list of items and definitions at the technical level of the classification.

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**Figure 1. Linguistic Analysis, List A**

**ITEM 1: Disease**

**Annotation:** Explore connotations related to sickness, illness, malady. Disease is understood as a definite diagnosis with a clear pathology. Differentiated from syndrome and disorder. Illness is more a social experience while sickness is a personal experience.

**Questions:** Do these distinctions hold true in your language? Are there different words for these different states?

**Translation:**

**Back-Translation:**

**Synonyms (local language):**

**Comments / Responses:**

**Figure 2. Examples: Linguistic Analysis, List B**

ID	ITEM PHRASES	
1	Transferring oneself	Everyday I transfer myself from my bed to my wheelchair.
	Seeing	have no trouble seeing the screen in a movie theater.
3	Using special means of communication	People who cannot speak may need to use special means of communication such as sign language.
4	Acquiring and applying knowledge	The school where I completed my secondary education was very practical in that we learned to apply the knowledge we had acquired through various tasks we had to perform.
	Dressing	I like dressing myself in different styles of clothing.
6	Experience of pain	I consider myself very lucky since I have never been hurt or experienced any pain.

The two analysis lists (concept and item) for the CAR linguistic evaluation contained 44 and 67 items, respectively. The conceptual list, List A, included key concepts and terms from the classification model, including umbrella and organizational terms, such as disablement, disability, disease, environment, and participation. It also included the key terms from the model description and the old classification, such as activity and handicap. The following box provides an example of the first item in List A, and its associated questions, that was presented for evaluation in the CAR study.

The second list contained the primary- or domain-level terms from the classification itself. It included terms and phrases such as mobility, transferring oneself, consciousness, or handling dangerous environments. Each of these items was accompanied by a sentence using the term and some synonyms. The following figure presents the first few items and their accompanying phrases as an illustration of the types of items included in the linguistic assessment process for List B.

The linguistic protocol for the ICIDH CAR required each site to do a complete translation of the Beta 1 draft ICIDH and to formally identify any items that proved difficult to translate. It also required that the introduction, all the research instruments, and Lists A and B be subjected to the full translation, back-translation, and evaluation protocol that were used in the pilot study. This process created a targeted linguistic analysis of the items identified as problematic, while also identifying new problem items. This targeted exploration allowed a relatively thorough but much more rapid assessment of the classification than would have been possible with a full back-translation protocol on all elements of the classification. The linguistic analysis report from each site provided the revision team with data that included the original English, the local language translation, and the back-

translation for both lists. The report described any basic cultural applicability questions for each item and noted any other linguistic problems encountered in the translation process. These data were then compared within and across sites to identify problem items and, in most cases, their solutions.

The majority of the ICIDH classification items were easily transferrable from culture to culture and language to language. However, as indicated in the pilot, there continued to be some problematic concepts in the ICIDH that exhibited one or more types of primary linguistic incompatibility.

Some concepts were difficult or impossible to translate in one of the CAR study languages because there is no equivalent term or cultural concept in the local language. Table 3 identifies examples of these types of ICIDH concepts, the linguistic issue, and the language in which the condition occurred for three examples.

**Table 3. Examples of Linguistic Equivalency Issues**

Concept or Phrase	Problem	Language
1. Affect	Does not translate	Hindi
2. Affect	No idiomatic equivalent	Kannada
3. Disablement	No generic term in Arabic	Arabic
4. Disablement	Cannot be used as umbrella term	Hindi
5. Executive function	Difficult to translate	Hindi
6. Executive function	Difficult to translate	Tamil

**Table 4. Examples of Concepts that were Partially Equivalent with English Terms**

Concept or Phrase	Problem	Language
1. Affect	Refers only to emotional state	Tamil
2. Affect	Not used in daily life, multiple meanings	Dutch
3. Affect	Partial overlap with sentiment	Romanian
4. Function	Translates as act, work, action	Kannada
5. Function	Means more an activity than anything pertaining to body organs	Romanian

There were a number of concepts that could be translated into one of the participating center languages, but the translation left out or added connotations to the translated terms. This makes the concepts only partially equivalent in the second language. Table 4 provides examples.

In some cases, this problem could be overcome by adding additional words or phrases to either expand or narrow the concept. In other cases, no satisfactory solution has been found for the shift in meaning, and other English words have been recommended for the original classification.

There were several words or phrases used to identify distinctly different conditions in English that lose those distinctions when translated into one of the languages of the CAR centers. For example, the words disease, illness, and disorder all translate into single words in Hindi and in Tamil. If these concepts are used in the classification system to distinguish different conditions, functions, processes, or elements of the classification system, then the loss of distinction through overlap has the potential for creating confusion between supposedly distinct categories when the classification system is used in other cultures.

Some items could be conceptually transferred to the other languages, but the definitions or examples needed to be modified to be cross-culturally applicable. There were a few terms and definitions that were inappropriate for use in one or more cultural contexts due to local cultural values and conditions. Some of these conditions were caused by cultural differences in environmental factors. There were also problems where the descriptions of particular disablements were culture-bound in the examples used in the definitions, such as the ability to step over a curb where no curb exists. The following two examples are representative of the culture-specific conditions that caused problems for the classification system.

*Keeping appropriate physical contact and maintenance of social space:* Problems with the examples of inappropriate touch or use of space in the definitions were identified by two centers in India. The idea of "social space" was

**Figure 3. Example of Pile Sort Card**

**TRANSFERRING ONESELF**

(moving oneself physically from one place to another adjacent one)

difficult to translate, and the conventions for touching or not touching are very different from European cultures. The recommendation was that examples need to be made generically culturally appropriate or left up to the local culture to describe

*Dating and forming relationships:* Dating is predominantly a Euro-American concept and is rare in a number of cultures, especially those where most marriages are still arranged. The recommendation was that the concept is not relevant in all cultures and the item should either be more generic or be optional as a category.

The combined analysis of each of the different kinds of linguistic problems encountered in the translation and linguistic-problem reports from the centers provided the basic data for revision of both the introduction and specific items in the ICIDH classification.

**Pile Sort Data Collection**

Pile sorting is a systematic technique to allow people to create an unconstrained and culturally appropriate classification of the important elements in a cultural domain (Weller and Romney 1988; Trotter 1997, 1991). The ICIDH CAR pile sort data collection was conducted using 90 cards that were preprinted at each site after translation and back-translation. Each card included one item name from the classification, a brief definition on the front of the card, and a code number (created in random order) on the back for data recording. The cards were placed in front of the respondent in nine vertical rows of 10 cards each.

The 90 items<sup>5</sup> chosen for the pile sorting and the concept mapping exercise represent all of the activity-level items (disabilities in the old classification) and all of the participation items (handicaps in the old system) at the two-digit (mid-complexity) level of the classification. This level is analogous to identifying all the detailed subheadings of the chapters of a book. It is the level of detail where it is possible to determine if any important concept is missing from the classification without overwhelming informants with details. In addition to the activity- and participation-level codes, a small number of the impairment-level codes, the complex impairments, were included. The following standardized instructions were given to respondents before they started the pile sort.

These cards contain words and phrases that are part of a classification of impairments, activities and social

participation conditions. Please look at all of the items, and place them in piles. You can make as many piles as you wish. Items should be placed together according to things that you feel make them alike, and they should be separated according to things that you feel make them different. You can use any reason you wish to create the piles.

After making piles, respondents were asked to review the piles to determine if any cards should be moved to another pile. A pile could consist of a single card. When they were satisfied with the pile selection, respondents placed a "pile name and group reason card" on top of each pile. The pile name and grouping-reason card provided verbatim rationales for why the items in the pile were grouped by the respondent and a label for the pile, if appropriate. The data were recorded on a data-record form.

Each site was requested to collect 30 pile sorts; 15 from health care providers, and 15 from persons with disabilities or caregivers for disabled persons. The health care provider respondents were to include 5 individuals who work with individuals who have physical disabilities and 10 individuals who work with individuals who have mental disabilities (including alcoholism and drug abuse). These individuals were broadly representative of the viewpoints associated with disablements in the culture. The consumer and caregiver group was to include both individuals with disabilities and individuals who are the immediate caregivers for persons with disabilities. The respondents were to include 5 consumers or caregivers who are affected by physical disabilities and 10 who are affected by mental disabilities (including alcoholism and drug abuse). These individuals were broadly representative of the viewpoints associated with disablements in the culture. A face sheet with demographic information was completed by each individual who did the pile sort exercise.

The raw data for each respondent were typed as an ASCII file and imported into the program ANTHROPAC 3.0 (Borgatti 1996), which has a data conversion routine that transforms raw pile sort data into an item-by-item similarities matrix. Matrix data were then analyzed using multivariate statistics. One of the analytical processes was a Johnson's Hierarchical Cluster Analysis of the pile sort data for both the individual-site data and a combined multisite data set. Comparisons were also made using the QAP analysis segment of the program. Evaluation of the cut points for the data identified a stable grouping of 17 clusters of items. The following set of classification items is an example of one cluster identified in the total data set. This represents the items included in the domain of interpersonal relationships, which was the most common label given cross-culturally on the pile label and rationale cards for this cluster.

BF Cluster 3 Interpersonal Skills (8 items)

- indent ] Keeping appropriate physical contact and maintenance of social space
- Interacting with an equal/coworker/peer
- Showing tolerance in relationships
- Interpersonal and social relationships (p)<sup>6</sup>

- Managing close personal relationships
- Managing relationships with friends
- People sharing living space (p)
- Keeping rules, abiding by decisions

The individual- and combined-site cluster data indicated that the structure of the classification system, as a whole, represents a cross-culturally stable organization of the relationships among these items. While some individual items are not yet cross-culturally applicable, the overall structure of the classification (i.e., the organization of the items into specific clusters within the classification) meets the needs and represents the composite viewpoint of both health professionals and individuals directly affected by disablements across very diverse cultures, language groups, and levels of economic development for the participating centers.

The combined ICIDH cluster pattern was checked for stability by removing randomly selected data from the complete data set. Four sets of randomly selected site cluster data were removed from the data set and then compared with the remaining whole data set. While there were some minor differences in the cluster solutions (some of the marginal items were more tightly associated with one cluster or another), a comparison of the modified set and the four site-specific data sets to the overall data, indicates that the clusters are stable in two ways. First, removal of sites from the database does not significantly change the cluster solutions. *Change would* Second, the cluster solutions for individuals' data sets are very similar to the overall data set. Both conditions support the strength of the original classification system. *sets*

The following conditions apply to the overall combined-site cluster data. The clusters correspond closely with many of the chapters of the ICIDH classification. This indicates that the classification has significant cross-cultural stability in its structure, since the piles that created these clusters were unconstrained (i.e., they were not created using cues about how to cluster them). Some items were very stable cross-culturally and are likely to be the best points for creating stable questions for cross-cultural disability-assessment questionnaires. The weakest items (those that are only loosely tied to a specific cluster) are those that have the least cross-cultural consensus about their placement. This indicates some form of cross-cultural ambiguity that needs to be resolved by changing, eliminating, or defining those items more clearly.

The cross-culturally unstable phrases and concepts identified by the pile sort process were ones that individual respondents had difficulty either understanding in the way they were intended or placing within the classification system in a way consistent with other pile sorts. Examples include the concept of "following (showing interest in) events that take place outside of the direct environment," "keeping appropriate physical contact," and "people sharing living space." Each of these items contains one or more conceptual elements that cause them to either be difficult to translate and be understood in several cultures, or they are elements that cannot be as easily associated with the other items in the classification

system. These items are being reviewed for either revision or removal from the concepts used in ICIDH. Other problematic items include: using public transportation; problem solving; understanding specific signs; psychomotor activity; energy and drive; and managing personal behavior.

In addition to the quantitative approach described above, the pile sort data were also analyzed using qualitative methods. As a test for cross-culturally ambiguous items, items individuals had a hard time placing in any pile (i.e., the "I don't know where it goes" items) were analyzed based on information given in the "reasons for pile sort and pile label" cards associated with each pile. An assessment list of these items that most commonly occurred in the "miscellaneous" piles demonstrated two types of difficulty for the classification: within-culture ambiguity and cross-cultural ambiguity. Items that were problematic within a single site were those that created confusion for more than one respondent. These and a second set of items that were identified in "miscellaneous" piles in multiple cultures are being utilized to target domain change in the revision process. These items provide a cross-check with the data derived from the mathematical models of the pile sorts and from the statistical analysis of the concept-mapping data analysis conducted for the CAR study. Results confirm that the items listed above as problematic match the ones that were ambiguous for the pile sorting and match the ones that showed the most cross-cultural difficulties in the concept-mapping exercise.

The comparison of each of these items to each other was important for two reasons. First, it allowed us to assess the boundaries between the three levels of the classification. Second, it allowed us to reconfirm that there were very few cultural problems with the elements of the classification that deal with body structure and function. The cross-cultural applicability problems all concentrate in the more complex areas of the classification.

## Concept Mapping

The concept-mapping exercise was designed to be an item-by-item cross-cultural applicability assessment of the same 90 items described above in the pile sort methodology. The only change from the pile sorting exercise was that the items were accompanied by a full operational definition, rather than the brief phrases utilized in the pile sort exercise. Concept mapping has been successfully used for item evaluation (Novak and Gowin 1984), and that purpose was maintained in this study. The concept-mapping instrument was presented in two versions. One was a paper and pencil version. The other was a questionnaire where data could be directly entered in the computer. The choice of which version to use was left up to collaborating centers.

Ten questions were asked about each item. The first two asked if the item needed clarification in the title or in the definition. The third question asked if the concept could be used without difficulty in the local culture. The fourth through seventh questions asked if the item could be used appropriately

and equally for all age groups, for both genders, for all social and economic groups, and for all ethnic or minority cultural groups in the society. The eighth question asked if the item was culturally sensitive (i.e., difficult to talk about, taboo, embarrassing). The ninth question asked where the item was best placed in the classification system (an impairment, an activity or disability, or a participation issue). The final question asked informants to rank the item's importance for retention in the classification system. The first eight questions allowed a yes or no answer, followed by an open-ended question asking for an explanation of any answers that indicated there was a problem with the item. The sampling framework for the concept mapping was identical to the sampling for the pile sort.

These data allowed researchers to apply several statistical analysis to the items. It also allowed the use of factor analysis to determine whether all 10 questions were necessary for evaluating the items, allowed cluster analysis to determine classification properties of the items, and allowed simple descriptive statistics to identify problematic items.

Overall, the concept-mapping data indicated that the ICIDH revision showed a high degree of cross-cultural compatibility. However, several points required accommodation in the classification revision. Most importantly, the classification of items into the three levels of the classification—impairments, activities, and participation—was not sufficiently clear to all participants. A total of 54.2 percent of the classifications were false in the sense that they did not correspond to the technical classification in the draft ICIDH. As a result, the new structure of the ICIDH and its underlying assumption had to be clarified and expanded so the preface will provide a better explanation of the three subdivisions of the classification.

Overall, the participation level (former handicap level) produced the most cross-cultural compatibility problems, especially with regard to usefulness of the items for different subgroups in a culture (e.g., age groups, gender, social groups, ethnic or minority groups). On the other hand, people made the least errors in classifying them into their appropriate level. Concept mapping also confirmed that items from all levels were seen as equally important for the ICIDH, and no level could be reasonably dropped at this time.

## Key Informant Interviews

The ICIDH CAR group identified a number of conceptual issues that could be best explored through key informant interviews at each of the sites. The key informant interview consisted of three related data gathering processes. The first was to ask key informants a series of open-ended questions. The second was to ask them to fill out a self-administered questionnaire. And the third asked them to complete a ranking exercise. A face sheet with demographic information was completed for each key informant.

Key informants were asked to answer questions in terms of what they thought was believed to be true in their culture, whether they personally agreed or not. The first three open-ended questions were designed to cover the range of terms

that exist in each local culture to describe disablements. The second set of questions presented four scenarios and asked key informants to respond to 10 semistructured questions about each scenario. The purpose of the scenario questions was to explore the issue of thresholds of awareness of disablement, thresholds of intervention, and issues of stigma and assistance for disablements in the local culture. The center principal investigators were asked to provide a qualitative summary of each of these interviews. The overall summary, in English, was provided in a question-by-question description of the responses from all of the informants. The summaries included the full range of responses and the most normative responses. Quotations that exemplified the most salient issues were requested for each question summary.

Following these open-ended questions, the key informants were asked to fill out a self-administered questionnaire consisting of two sections. In section one, the key informant was presented with four scenarios parallel to the ones in the semistructured interview. One example is given below:

**Scenario 1:** Think of a person who is confined to a wheelchair because of a spinal cord injury. The person gets around in the wheelchair but an attendant has to take care of most everyday tasks, like personal grooming.

For each scenario, the informants were asked to check off answers to two questions for each of 10 activities. The questions were: "How surprised would people be if this person did this activity?" and "Is it likely that anyone would place restrictions or barriers on the person doing this?" Each question utilized a four-point scale, from low to high. The 10 comparative conditions were all activities from ICIDH. They included: 1) keeping things tidy in the home; 2) using public transportation; 3) being in love; 4) having sex as part of a relationship with someone; 5) actively taking on parenting roles; 6) actively taking part in community fairs and festivals; 7) managing their own money; 8) getting an apartment or somewhere to live; 9) keeping a full-time job; and 10) being elected or named to a position in local government. The data for these responses were provided to WHO for quantitative analysis.

After key informants completed the questionnaire they were asked to take 17 cards, each with a different health condition and description of that condition, and rank them from the most disabling (1) to the least disabling (17).<sup>7</sup> Each person was asked to think of the most disabling condition as the one that would make carrying on the activities of daily life very difficult (such as eating a meal or getting around), and the least disabling would be that which would not interfere with the activities of everyday life. The ranking data were submitted to WHO for quantitative analysis.

The sample design for the key informant interviews was different from that for the pile sorting and concept-mapping data collection process. A total of 15 individuals were to be chosen for the key informant interviews, divided into 5 subsamples. The individuals chosen for each subsample were to be as broadly representative of all viewpoints about

disabilities as possible. This ethnographically representative sample was to include three individuals who are medical professionals, three who are disability specialists, three who have a disabling condition, three who are caregivers to persons with disabilities, and three individuals who are policy makers in the area of disability services.

The key informant interview data consist of a complex data set that is allowing both qualitative and quantitative data analysis to be conducted for all the sites combined and within particular sites. Up to now, the analysis has focused on the quantitative data, since it is easier to quickly analyze. The first examination of these data has contributed a nuanced picture of the relative cultural assessments of physical, mental, and alcohol and drug disablements with respect to degree of stigma, the reaction to a person with a particular disablement appearing in public, the degree of disabilities associated with specific disablements, and the level of barriers faced by people with specific conditions engaging in a range of 10 social activities. In general, the results contribute to our understanding of "parity": the extent to which different disablements are treated the same. According to the key informants, no society has attained parity. There are substantial differences in the rankings on parity, but in general those with physical disablements or cognitive impairments are reported to encounter less stigma and discrimination against social participation than do those with alcohol, drug, or other mental disorders.

Mean ratings of social disapproval were calculated for each of the health conditions listed. The overall ranking shows that across societies, those in wheelchairs, those who are blind, and those who cannot read receive the least amount of social disapproval, while those with an alcohol problem, HIV, a criminal record, or drug problem receive the highest level of disapproval.

A series of one-way ANOVA procedures was performed on the means for the ratings, looking at differences among eight countries using the Scheffe test at the .05 probability level. Differences were found for 7 of the 18 health conditions. For example, significant differences were found between certain countries regarding social disapproval ratings for obesity. Those in the United Kingdom gave higher ratings indicating more stigma, compared to those in India and Tunisia. Similarly, those in Canada gave higher ratings than those in India. Nigeria gave greater disapproval ratings for depression than did India. Homelessness received greater disapproval in Canada than in Egypt and India. Each of these comparisons is being combined with the qualitative data from the open-ended questions of the interview to improve both the analysis and interpretation of these findings across cultures, and within them, in support of revision of the classification.

The study also included an expert ranking of disablements based on the degree of disability associated with each. This was a key rapid assessment substudy that in part replicated the expert ranking exercise carried out at a WHO/World Bank meeting in 1995 and reported in Murray and Lopez (1996:39). The combined ranking of disablements, taking the CAR informants as a whole, was exactly the same as reported

by Murray and Lopez for 11 of the 12 conditions ranked in the 1995 study, using different approaches. Migraines were differently described in the two studies, leading to a probable difference in ranking. In the ICDH CAR study, alcoholism and drug dependence ranked in the middle of the list as more disabling than severe migraines or mild mental retardation, but less disabling than major depression, active psychosis, or dementia. As in Murray and Lopez, there were few physical conditions that ranked as high as severe mental illnesses in the degree of disability (impact on individual and society) attributed to them.

## Focus Groups

Each site was originally asked to conduct two out of three possible focus group studies, consisting of two focus groups per study per site. This requirement was later made optional, since not all centers were able to complete the focus group data collection and analysis in the time allowed for the field study. The first focus group option explored the underlying model of the ICDH-2 classification. It was designed to be conducted with health and social service professionals who would be involved in the use and dissemination of the ICDH classification. The second study option was to explore the stigma attached to disablements in each culture. These focus groups were conducted with persons experiencing disablements and with the family members of persons with disablements. The third study option was to explore the current institutional needs related to disablements. These focus group were to be conducted with individuals who have experienced disablements, individuals who have extensive knowledge of the disablement service system, and individuals who are knowledgeable about the needs of persons with disablements in the society. The actual focus group guides (questions and probes used at all sites) are available from WHO Geneva. One example is given below:

### Basic Issue 2: Parity and Stigmatization of Disablements

This study allows a cross-cultural comparison of the ways in which individuals with disabilities are viewed, assisted, potentially stigmatized, and allowed or denied access to social participation within various cultures. This study is targeted at gaining information from the general public in each culture, and from the family members of individual who have disablements. This provides the opportunity to add the viewpoints of family members and of the general population as a supplementary part of the overall cross-cultural assessment of disabilities. This process will also allow the views of health and social service professionals to be contrasted with the views of the general public, family, and individuals with disablements.

The full data set will be reported elsewhere; however, results from four reporting sites are presented here as an example of the areas of cross-cultural applicability that were explored using this method. The information includes data on the ICDH model, on parity and stigmatization, and on the current practices in various cultures.

## ICIDH Model

There is a clear need expressed for the existence of a revised classification and general agreement on the issues that need to be clarified. These issues were described in the introduction to the revision process. There is no consensus apparent on how the model should be graphically described or drawn, but there is not significant opposition to the proposed description of the model. Within the medical establishment, there is a focus on diagnosis in place of impairment and activity. The somewhat opposing view that the focus of the classification should be on the consequences of health conditions, not on the health conditions themselves, is strongly represented in the consumer and disability advocacy participants in the focus groups. The proposed model for the ICDH stands up reasonably well, with a need for minor revisions or changes in emphasis, based on the preliminary focus group data analysis.

no stack

## Parity and Stigmatization

The overall findings indicate that the ideal of parity between physical and mental health disablements is a relatively new concept, both for professionals and for persons affected by disablements. In all the focus groups it was clear that disabled people are stigmatized, avoided, and harmed by the public perception of their abilities and disablements. Physical and sexual abuse of individuals with disabilities was reported in a number of cases. The attitudes and behavior of family in relation to disabilities are seen as very complex. In many cases, stories of support, sympathy, and outstanding levels of responsibility are reported. There are also contrasting cases of disgust, neglect, and harm, although in much smaller proportions to the overall population. In long-term disabilities, the family often has very low expectations for the person with disablements and may even remove responsibilities the person could and should accommodate. There were some significant differences in attitude reported between individuals with mental problems and those with alcohol and drug problems. In the latter case, the problems were more likely to be thought to have been generated by the person, and be the person's responsibility, than in the former case. This reflects the general trend for the societies studied as a whole.

The focus group data indicate that the majority of individuals in the workplace avoid individuals with disablements and find it difficult to work with them. This discomfort increases significantly with mental disablements and is very highly stigmatized with alcohol- and drug-related disablements. There is individual variability in this issue, but, for the most part, persons with disablements receive high degrees of work discrimination and avoidance. Focus groups noted that the families of individuals with disablements are often also the recipients of the stigma and avoidance associated with the individual who has the disablement. The individuals' prospects for marriage are greatly diminished, and, in those societies where marriage has retained many of its traditional functions, the family may be harmed in terms of other children having the opportunity for advantageous marriages.

## Current Practices and Needs

The data from the current practices and needs focus groups parallels the data from the parity and stigma focus groups in many ways. Part of the data from both data sets will be compared and contrasted to answer both sets of questions. The amount of information that focus group participants have about the law and the availability of services varies widely. Overall, both health professionals and individuals with disabilities have limited knowledge of the systems that exist in each of the cultures studied. Individuals with disabilities, and their caregivers, seem to have the most knowledge about the programs, services, laws, and conditions that are directly related to the disabilities that affect them. They tend to be more knowledgeable in these areas than many of the health professionals. The health professionals have extensive knowledge about the disabilities that affect their area of specialization, but have limited knowledge (and occasionally no knowledge) of the laws, the social service programs, or the advocacy and self-help groups that are associated with various disabilities. There is a clear need for education in this area.

Participants indicated that many of the laws and programs on disabilities focus on categorical conditions—programs for the blind, deaf, physically immobile—and not on disabilities in general. The result is a wide range of sometimes conflicting or noninteracting programs. In addition, there is a clear disparity in the stigma attached to different disabilities; disabilities associated with mental health conditions and addictions are the most stigmatized and the least likely to receive adequate services or funding.

All participating centers reported significant benefits for their programs derived from the focus group data collection and analysis. Some of the preliminary recommendations for instrument development are: 1) including sufficient mental health or related items in the instrument to begin to determine the empirical basis for parity between physical and mental disabilities; 2) creating the means to assess different levels of stigma attached to the physical and mental disabilities demonstrated by the focus groups; and 3) investigating the place of alcohol and drug abuse in the production of both physical and mental disabilities.

## ICIDH CAR Contribution to the Revision of ICIDH

The ICIDH CAR effort was successful in providing useful data for revision of the ICIDH. It identified key issues about the model underlying the classification and contributed to direct modification of items in the classification. The data continue to provide invaluable direction for the development of assessment instruments linked to ICIDH. The following sections briefly summarize the types of results and actions that were made possible by the cross-cultural research methodology. Full reports on each individual method will be published separately.

## Center Description Reports

The center description data were used to improve the structure and content of the Revised Draft ICIDH, especially the introductory material. The need for the classification was clearly established through evidence that the concept of disability existed in all centers, accompanied by some form of legislation and benefit system. One important finding from these investigations is that the most crucial dimension of classification, from the perspective of social assistance systems, is not the specific type of disability but the availability of a unidimensional “measure” or assignment of “degree” of disability, often expressed in percentage. This finding indicates that the revised ICIDH will find wider acceptance in these systems if it lends itself to a summary determination of “degree of disability.” This finding suggests that the revised ICIDH and its associated assessment instruments should directly deal with the systemic need for defining and measuring thresholds where a disability “counts” as significant and in need of intervention. In addition, the need to include environmental factors as important determinants of the disablement experience was clearly emphasized by the fact that disability was indeed experienced differently in the different settings where the study was carried out.

## Linguistic Information

There were several ICIDH concepts and terms that exhibited problems in more than one of the types of linguistic conditions reported by the centers. These multiple-problem items are being carefully addressed during the revision of the classification and instrument development for cross-national comparison of items. There are others that present problems in a single language and those conditions will need to be addressed in that language only. The options are to use a borrowed term for concepts that do not exist in the language but can be borrowed from another language; to add descriptive phrases or modifications to an existing term that captures the meaning in the original; or to combine existing words into unusual new combinations that can be used to explain the concepts in the classification. Parts of the classification system may not be culturally applicable in a small number of cultures. Those specific items may need to be ignored at this time in those cultures. It will be important to note those areas of incompatibility and to deal with them appropriately during instrument development for epidemiological and policy purposes.

The linguistic exercise also emphasized a very important need for changing the elaborate and complex English text in places and converting it into “plain English.” This change allows the classification to be more accessible to its many different constituencies or users; it also facilitates the work of translators for future versions. Thus, the linguistic exercise not only served to provide better translations; it also ensured that the English text was revised adequately and that concepts that were clearly inapplicable in several settings were not retained within the core classification.

## File Sort Data Analysis

One of the interesting findings of the pile sort results was that respondents did not create associations based on whether an item described an impairment, an activity, or a participation issue. They clustered items that tapped different facets of the same concept or construct. The core of the clusters were common life activities (daily activities like food preparation), with associated impairment and social participation items being added later to the cluster (based on the hierarchical relationships described by the cluster analysis). This tendency has important implications for instrument development. It suggests that assessments of disablement ought to use activity- or disability-related items as the entry point for enquiry, but need to be informed by the fact that respondents often take the level of impairment and participation into account while responding. Thus, assessments ought to attempt to tease out the three concepts as a later step in a branching algorithm for interviews.

The pile sort technique is ideal for comparing cross-cultural views on classification systems. The following recommendations and actions are resulting from this data set. The items that show a clear cross-cultural stability and high saliency in the cluster analysis are strong candidates for anchors for instrument development to assess the ICIDH domains or to use in a short form for assessment of the population. Items for the ICIDH epidemiological and assessment instruments should be drawn from the high-stability items demonstrated for the pile sort cluster analysis. We also recommend that those items that show the least stability in the pile sort analysis be modified during the revisions of the ICIDH and be avoided as core items for instrument development. The underlying dimensions demonstrated by the multidimensional scaling of the pile sort data indicate that the overall structure of the classification includes: 1) the concept of simple to complex domains, based on complexity of task and cognitions; and 2) the domains recommended for instrument development capture the majority of the underlying principles embedded in the classification system.

The new version of the classification takes into account all these conditions. The items related to interpersonal relationships were reordered and modified to reflect the results of the pile sorting. They were changed in the revision to reflect that items like general interpersonal skills need to be differentiated from maintaining specific relationships, such as intimate relationships. It was important to reflect the different nature of close versus distant or formal relationships. It was also clear that intimate and sexual relationships need to be separated out from other forms of interpersonal relationships, at least in part because of common difficulties in discussing these issues in various cultures.

## Concept-Mapping Results

The concept-mapping data were used to improve the structure and content of the Revised Draft ICIDH. Based on these data, the participation items were extensively rewritten to tap those common denominators that would be universally applicable. This required considerable modification of descriptions and illustrations in the classification to assure that the underlying concept was clear and could be used in different cultures by analogy rather than homology. Moreover, the questions in the concept mapping were analyzed by factor analysis resulting in five questions instead of ten for the next phase of field tests of the ICIDH. This was possible since it could be shown that the clarity of item and concept-definition correlated highly enough to be combined into one question, and the five questions on usefulness could be combined into only one question (useful in culture, for all age groups, for both genders, for all social and economic groups, for all ethnic and minority groups). The remaining three questions addressed different dimensions and were retained for the next phase of field tests.

## Key Informant Interviews

The key informant data identify several cultures in which terms such as disablement, impairment, disability, handicap, or participation do not exist independently to describe different social constructs. This highlights the need to build an agreed-upon vocabulary that provides a common language for communication in this field internationally. The data highlight the fact that stigma varies between different cultural contexts and that no parity exists between mental and physical conditions in terms of societal acceptance or compensation mechanisms. The philosophical principle derived from these data is the determination to retain an "etiology neutral" framework for the ICIDH revision. This approach will avoid creating a false dichotomy between "physical" or "mental" disabilities by creating a description of activity limitations and multifaceted profiles of disablement associated with underlying health conditions rather than simple summative mental and physical labels. Thus, the ICIDH should serve as a tool to document the extent of disablement irrespective of etiology.

## Focus Group Report

The focus group data complement results from other methods. It can be interpreted as supporting the need for a version of the ICIDH that can be used universally across professional disciplines, patient populations, treatment settings, and cultures. It also provides an important reinforcement for the movement to produce better parity between mental and physical disabilities in relation to the items in the classification as well as the overall model of disablements.

## Conclusions

The ICIDH CAR methodological configuration has proven highly productive and useful in the revision of the Draft ICIDH. The amount of data was enormous. The initial use of those data, to inform the revision of the ICIDH, will continue to produce positive results for some time to come, as a new version of the ICIDH is adopted by the Plenary Revision Group (centers, task forces, and advocacy representatives). At the same time, the data from each of the research methods and each of the centers are being analyzed for both the theoretical and pragmatic insights that each one provides on its own. Individual centers and combinations of centers are completing analysis for publication of their local data sets and cross-cultural comparisons of data sets that deal with the larger issues of understanding disablements and the cultural processes of dealing with disablements around the world. This information is already being disseminated at meetings.<sup>8</sup> Anecdotal reports from each of the participating centers indicate that several of the methods produced unexpected learning opportunities beyond the simple data collection. The pile sorting exercise was considered fun by most of the participants. It also provided interesting additional information about the classification, due to the natural tendency of people to talk to themselves or to the interviewer while they are doing the pile sorting. The focus groups were particularly powerful in providing the center researchers with insights into the public and the professional views of disablements in their cultures. Three of the data sets provide powerful confirmations of individual-method findings (triangulation). The linguistic, pile sorting, and consensus-mapping data are each valuable in their own right, but are more powerful when both the qualitative and quantitative findings are combined. The combined findings identify the items in the classification that are the most stable across cultures and those items that are the most problematic. These items have informed the instrument development that is currently ongoing. The major goal of this phase is to produce a cross-culturally valid instrument to measure disablement and functionality limitations compatible with the ICIDH. The triangulation also identified the boundary areas between the three levels of the classification and the items that need improvement to move from stable to highly stable in the system. In summary, this combination of ethnographic, rapid assessment, and statistical methods produced the results needed at each stage of the revision process and promise to continue providing valuable recommendations, interpretations, and innovative directions through to the final adoption of the ICIDH by the World Health Council.

### Notes

<sup>1</sup>These centers are the three original WHO collaborating centers in France, the Netherlands, and the North American Collaborating Center, which includes collaboration between the U.S. Center for Health Statistics and Stats Canada.

<sup>2</sup>Each task force consists of a panel of international experts drawn from each of the six WHO regions. These meet on at least an annual basis and provide input on their selected area to the overall plenary group. The task forces include the Mental Health Task Force, the Children's Task Force, and the Environmental Task Force.

<sup>3</sup>The centers that completed all six data collection tasks included three sites in India (Bangalore, Chennai, and Delhi), Japan, the Netherlands, Nigeria, Romania, and Tunisia. Tunisia was responsible for data collection in Egypt, so there was no separate center narrative for Egypt. The centers that collected all except the focus group data included Canada, China, Greece, Luxembourg, Spain, Turkey (with sites in Ankara, Istanbul, and Antalya), and the United Kingdom. The U.S. site (Flagstaff, Arizona) did not collect key informant interview data or concept-mapping data. The sites that collected focus group data included the three sites in India, Japan, Netherlands, Nigeria, Romania, Tunisia, and the U.S.

<sup>4</sup>The centers and languages included: Bangalore, India (Kannada); Madras, India (Tamil); Delhi, India (Hindi), and Santander, Spain (Spanish).

<sup>5</sup>The following are the Pile Sort and Concept Mapping Item List, Code Numbers, and Indication of Classification Level in the ICIDH (C = impairment, A = activity, P = participation): 1 Transferring oneself - A; 2 Community - P; 3 Seeing - A; 4 Memory - I; 5 Attention - I; 6 Mobility - A; 7 Thought, Abstraction, Judgement, and related executive functions - I; 8 Using special means of communication - A; 9 Acquiring and applying knowledge - A; 10 Dressing - A; 11 Experience of pain - I; 12 Interacting with an equal/coworker/peer - A; 13 Recognizing directions in space and time - A; 14 Keeping appropriate physical contact, and maintenance of social space - A; 15 Leisure - P; 16 Understanding specific signs - A; 17 Economic self-sufficiency - P; 18 Nonverbal means of communication - A; 19 Visual sensory functions - I; 20 Use of communication devices - A; 21 Perception - I; 22 Civic and community life - P; 23 Showing tolerance in relationships - A; 24 Keeping self clean and appropriately groomed - A; 25 Hearing - A; 26 Hearing functions - I; 27 Organizing daily routine - A; 28 Taking care of one's health - A; 29 Temperament and personality - I; 30 Eating and drinking - A; 31 Interpersonal and social relationships - A; 32 Maintaining physical environment - A; 33 Managing a dangerous environment - A; 34 Arithmetic activities - A; 35 Managing close personal relationships - A; 36 Handling everyday physical environment - A; 37 Managing relationships with friends - A; 38 Motor coordination - I; 39 Citizenship responsibilities - P; 40 Performing an activity for an extended period (psychological endurance) - A; 41 Orientation - I; 42 Self-care - A; 43 Intellectual development and function - I; 44 Consciousness - I; 45 Moving around - A; 46 Work - P; 47 People sharing living space - A; 48 Following written instructions - A; 49 Expressing empathy - A; 50 Problem solving - A; 51 Planning/organizing meals - A; 52 Cultural activities - A; 53 Handling technical devices/aids for locomotion - A; 54 Use of humor - A; 55 Communication activities - A; 56 Changing a body position - A; 57 Affect - I; 58 Following (showing interest in) events that take place outside of the direct environment - A; 59 Study behaviors - A; 60 Recognizing - A; 61 Written communication - A; 62 Managing general psychological demands - A; 63 Taking care of pets/domestic animals - A; 64 Communication content - A; 65 Activities related to fulfilling of financial obligations and services - A; 66 Maintaining a body position - A; 67 Cooking, baking, frying solids - A; 68 Conversation processes and structure - A; 69 Abilities relating to learning and communication - A; 70 Taking care of meals - A; 71 Dating and forming relationship - A; 72 Energy and drive - I; 73 Religious activities - A; 74 Psychomotor activity - I; 75 Handling body-attached technical aids - A; 76 Keeping rules, abiding by decisions - A; 77 Sexual functions - I; 78 Washing oneself - A; 79 Following verbal instructions - A; 80 Education - P; 81 Language - I; 82 Work acquisition and retention behaviors - A; 83 Performing consensual sexual acts - A; 84 Procurement and

care of necessities - A; 85 Responding to conversational cues - A; 86. Taking care of household or family members - A; 87 Monitoring and evaluating performance of activities, tasks - A; 88 Managing personal behavior - A; 89 Using public transport - A; 90 Responding to dangers - A.

<sup>6</sup>Items with (p) behind them were part of the participation (formerly handicap) section of the classification. Items from the impairment section were followed by an (i). Activity items were not followed by a label.

<sup>7</sup>Health conditions and descriptions were (in order of presentation): *active psychosis*: having delusions, hearing voices, unable to speak in clear sentences; *alcoholism*: being unable to control one's drinking, even though it causes problem in one's life; *below-the-knee amputation*: one leg is amputated below the knee; assuming no artificial leg, but having crutches; *HIV positive*: being infected with the virus that causes AIDS, but without the major symptoms of AIDS; *infertility*: wanting a child, but being unable to have one; *major depression*: the loss of interest or pleasure in nearly all activities, decreased energy, feelings of worthlessness, difficulty thinking, concentrating, and making decisions; *mild mental retardation*: having lower than normal intelligence (say an IQ between 55 and 70, where the average IQ is 100); an adult having a mental age range between 9 and 12 years old; *paraplegia*: the lower half of the body is paralyzed, including both legs; assuming access to a basic wheelchair; *quadriplegia*: both legs and both arms are paralyzed; assuming access to a basic wheelchair; *severe migraines*: having continuous severe headaches for one year, often being bed-ridden; *total blindness*: being unable to see at all; *total deafness*: being unable to hear at all; *vitiligo on face*: having at least 10 percent of the face afflicted with permanent depigmentation (white patches).

<sup>8</sup>For example, a comparison of the data from the Bangalore, Delhi, and Madras sites has been presented at the annual conference of the Indian Psychiatric Society in January 1998, and information on the cross-cultural comparisons was presented at the Society for Applied Anthropology meetings in April 1998.

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