

# Chapter 3

## Cross-Cultural Applicability Research (CAR) Methods

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### Introduction

Revising an international health classification presents a number of challenges that impose a balance between methodological demands and cultural imperatives. The classification must be based on a natural or consensual framework that makes it useful for multiple purposes (e.g., policy development, health communications, epidemiological research, or third party payment systems). It should accommodate significant differences between cultures based on language, belief, physical conditions and values. It needs to be successfully translated into local languages with perfect or near-perfect correspondence of all of its items. It has to contain concepts that are found, or can be explained, in local cultures. It must be useful to local cultures. And it needs to allow correct comparisons of conditions in the local culture with conditions in all other cultures.

These conditions require that the revised *International Classification of Functioning and Disability (ICIDH-2)* and the instruments based on it that are developed to assess disabilities be conceived in a common way across cultures. The classification must be open to what cultures tell us about what does and does not work, while satisfying the need for a universal perspective. This formulation is constantly challenged by demands that a new word be created, and old prejudices not be embedded in the concepts, terms, and language we use to describe disabilities. The natural tensions of the revision process therefore create the need to compromise between universalist tendencies and local cultural relativism, while maintaining each at an appropriate level in the classification.

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The CAR study addressed this multidimensional challenge by pursuing a number of objectives matched to multiple methods that allowed triangulation of data. It recognized the need to gather information on the scope and operation of disability support systems and other social services in different societies, including information on the criteria and processes that are used to assess disability. It allowed us to investigate the social conditions attached to disabilities. For example, there is significant cross-cultural variability in the stigma attached to disability and the acceptability of the participation of persons with disabilities. The study offered an opportunity to measure these differences for a spectrum of conditions, with particular emphasis on issues of parity in social regard and handling of physical disabilities on one hand, and mental disability and those associated with alcohol or drug use on the other.

Since the ICIDH-2 presents a paradigm shift in its definition of disability, compared with the 1980 version of ICIDH, it was felt that there was a need to test the recognizability and acceptability of the new theoretical construction for disabilities in different cultural contexts, as well as exploring the relation between commonly used terminology for disability in different languages and the terms and concepts proposed in that conceptual framework.

The revised ICIDH-2 has been built as a nested hierarchical classification of categories of functioning. Therefore, it was decided that testing its applicability cross-culturally required assessment of the meaning and meaningfulness of the proposed categories, definitions, and logical placement within the classification. This included determining if the different terms used in the classifications were translatable, if they carried the same meaning in different cultures, and the extent to which different cultures shared the clustering of concepts and terms implied by the hierarchical structure of the classification.

The project also needed to investigate the issue of cross-cultural differences or similarities in the thresholds of identification of disabilities. A disability may be a departure from general cultural expectations about a person's condition, behaviour, and social involvement. Therefore it was necessary to explore the threshold at which a disability is identified as significant and considered serious enough to warrant assistance or other social response, since these thresholds may differ between cultures, even when there is no problem in translating or understanding terms and concepts. The following sections provide details on the methods, types, and ranges of data collected in the study.

## Centre description on disabilities

Each CAR centre was asked to respond to questions designed to describe the local situation concerning the conceptualization and handling of impairments and disabilities. The purpose of the resulting report was to compare the context of disability conditions across the sites.

The questionnaire used was divided into three sections. Section 1 requested information about the general cultural view of disabilities in the society. It explored the terminology used for general categories of disability. It also explored the presence or absence of parity between physical and mental disabilities in law, public and private benefits, insurance, health services and public opinion. It asked the centre to identify advocacy and charitable organizations that deal with disabilities. Section 2 of the centre description questionnaire asked for information on disability compensation and support systems in the society, focusing on support and benefits available at the specific study site. In Section 3 the questionnaire turned to specific social systems that commonly exist - namely, workers' compensation system, support for current and former military personnel, and general rehabilitation system - as an index of the degree of societal variation in conceptualization of and support for disabilities.

No formal sampling plan was specified for the centre description, though site investigators were encouraged to seek information and assistance concerning the different societal systems from others as needed. In effect, the site investigator responsible for preparing the centre description at each site served as a key informant on the site. A substantive finding from the process was how fragmented local knowledge of disability matters often is. At many sites, filling out the centre description required a lengthy series of phone calls and other enquiries.

## Translation-back translation and linguistic analysis protocol

### *Pilot study*

A brief pilot study was conducted for the CAR project at six centres. Four centres were asked to do a complete translation/back-translation protocol for the entire draft revision of the classification. The translation was conducted by professional translators who also had some familiarity with the ICIDH-2. The back-translation was conducted by experienced translators who were not familiar with the ICIDH-2, and who had not seen the English version of the classification before to seeing the local-language version. Each item that

was back-translated differently from the original (even when the translator used a very close English synonym) was identified and discussed, and a recommendation for reconciliation was made. This process determined that the majority of the ICIDH-2 concepts and items were stable and did not show significant linguistic or cultural divergence, even between very different language groups.

However, the pilot study did identify two areas where problems consistently occurred: Many problems were discovered in the new introduction to the revised classification, which discussed the changes in the conceptual model of disability for the classification. This text had not gone through an iterative process in its development. Second, there were a number of items in the classification that were consistently problematic across sites and languages. These were domains and items in the classification that were linguistically difficult or culture-bound. This produced two lists of items needing further linguistic exploration. One was a list of concepts and phrases at the conceptual level of the classification; the other was a list of more technical items and their definitions.

### *Linguistic analysis protocol*

The pilot study resulted in the recommendation that the CAR linguistic analysis protocol require each non-English-language site to do a complete translation of the Beta-1 draft of the ICIDH-2, including the introduction. A further requirement was that the introduction, all of the research instruments, and the two lists of key items be subjected to the full translation/back-translation and evaluation protocol that was used in the pilot study. This process ensured the completion of a targeted analysis of the items that had already been identified as problematic (after they had been changed for the Beta 1 draft). It also allowed the centres to identify new problems through the process of translating the complete ICIDH-2, since the revised protocols called for identifying, summarizing, and reporting on all linguistic problems encountered in the translation and translation review process. This revised targeted linguistic exploration did not place the burden of a complete translation/back-translation protocol on the centres, but it allowed a thorough and much more rapid assessment of the classification.

The two lists provided for translation, back-translation, and evaluation contained 44 and 67 items respectively (see Appendix A). The conceptual list, List A, included all of the concept-terms from the introduction shown in the pretest to have posed cross-cultural problems in meaning or linguistic transfer. This included umbrella and organizational terms, such as "disabil-

ity," "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 linguistic data summary sheet provides an example of one of the problematic items, and the data to be recorded on it, from 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 1.* Linguistic analysis List A: conceptual terms data summary sheet

The second list of items (List B) included in the full linguistic analysis protocol contained terms at the two-digit level from the three classifications (Impairment, Activity, and Participation) as they appeared in the Beta-1 draft revision of ICIDH-2. The list included terms and phrases such as mobility, transferring oneself, consciousness, and handling dangerous environments which had been shown to be problematic in the translation pilot study. Each of these items was accompanied by a sentence using the term and some of its synonyms. The centres were asked to translate the item, phrase, and synonyms, and provide feedback on any problems. Figure 2 provides an example of the first six items and their accompanying phrases, from the complete list identified in Appendix A.

ID	ITEM	PHRASES
1	Transferring oneself	Everyday I transfer myself from my bed to my wheelchair.
2	Seeing	I 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.
5	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 pain.

Figure 2. Linguistic analysis List B: expert or technical terms

### Linguistic analysis report

The linguistic analysis report from each site provided data on the original English, the local language translation, and the back-translation for both lists. The report also summarized the basic cultural applicability questions for each item, and noted any other linguistic problem encountered in the translation process. These data were then compared within and across sites to identify problem items and, in most cases, their solutions.

### Pile sort data collection

The pile sort data collection was conducted using 90 cards preprinted at each site. At non-English-language sites, these items were translated from the original English-language data set using standard linguistic protocols. Each card presented one item from the ICDH-2 classifications, including the item name and a brief definition on the front of the card, and a code number (created by a random table of numbers) on the back, for data recording. The cards were placed in front of the respondent in nine vertical rows of ten cards each. The layout was standardized according to the random number order, to prevent differences between respondents due to differences in the stimulus presentation pattern. The following example is one of the pile sort cards, from the original English data set.

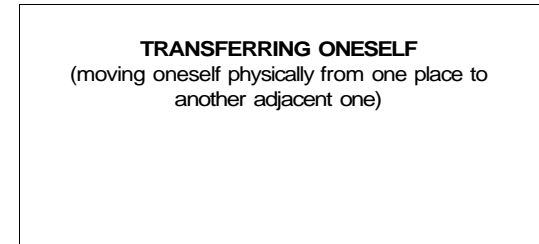


Figure 3. Sample pile sort card

### Pile sort items

The 90 items chosen for the pile sorting (and the concept mapping) exercise represent all of the activity and participation items at the two-digit level from each classification. This level is analogous to 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 classifications, some complex impairments from the impairment classification were included, at the recommendation of the centre heads and WHO research team.

### Pile sort data collection instructions

The following instructions were given to each respondent, before starting the pile sort:

"Instructions to be read: 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."

When the respondents had finished sorting the items into piles, they were asked to review the piles to determine if any cards should be moved to another pile. They were told that a pile could consist of any number, from a single card to as many cards as they wished. 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 was filled out according to the rationale they used to create the pile. The complete data were recorded on a data record form using the format shown in Figure 4.

# Informant Identification Information
Pile 1: 1,3,90,57,88,63 Pile name: [name given to pile] Reason for pile: [reason for putting cards together]
Pile 2: ...etc.

Figure 4. Pilesort data recording form

A face sheet with demographic information was completed for each individual who provided data for the pile sort exercise.

Each site was requested to collect pile sorts from a total of 30 persons - 15 from among medical or other health professionals, and 15 from among persons with disabilities or caregivers for disabled persons. The health care provider respondents were to include five persons who worked with individuals who had physical impairments, and 10 who worked with individuals who had mental health (including alcoholism and drug abuse) impairments. It was specified that these individuals were to be broadly representative of the viewpoints associated with disabilities in the culture. The consumer and caregiver group was to include both individuals with disabilities and individuals who are the immediate caregivers for such persons. The respondents were to include 10 consumers or caregivers affected by physical impairments, and 10 affected by mental impairments (including alcoholism and drug abuse). Again, it was specified that these individuals should be broadly representative of the viewpoints associated with disabilities in the culture. Sites were informed that if they wanted to do within-site comparisons, these sample sizes needed to be expanded to approximately 20 individuals per group to be compared.

## Concept mapping

The concept mapping exercise was designed to be an item-by-item cross-cultural applicability item assessment of the same 90 items investigated in the pile sort methodology.

### *Items used for concept mapping method*

The only change in the items used in the pile sorting exercise, was that they were accompanied by a full operational definition, rather than the brief phrases utilized in the pile sort exercise. Concept mapping has been successfully used in single-culture studies for item evaluation, and that purpose was extended in the CAR study to a multi-culture design. The questions concerning each item and some of the analytical strategies were changed to meet the needs of a cross-cultural applicability study.

The English version of the 90 items was made available to collaborating centres in two versions. One was a paper and pencil version. The other was a computer database, where an informant's responses could be directly entered on the computer. The choice of which version to use was left to the preference of the collaborating centres. Both versions were fully compatible with translation guidelines. However, there were many technical difficulties with the computerized version, which made data collection through that means much more time-consuming than the paper and pencil version. The result was that most of the data were collected by paper and pencil methods.

### *Concept mapping item questions*

Ten questions were asked about each item. These questions were designed to establish the cross-cultural applicability of the item, its correct placement in the classification, and its importance to the classification. The first two questions 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 to 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 (e.g., difficult to talk about, taboo, embarrassing). The ninth question asked where the item was best placed in the classification system (as an impairment, an activity, or participation issue). The final question asked the

informants to rank the question, in terms of how important it was to keep the item in the classification system. The first eight questions allowed a yes/no answer, followed by an open-ended question asking for an explanation of any answers that indicated that there was a problem with the item. An example

### 1 Transferring oneself

*Changing body position in order to get from one location to another, for example from a bed to a chair or moving over in the same bed or chair. It should be noted that disability in transfer activities might arise both for physical and psychological reasons.*

1. Does this item need clarification in the title? 1. Yes 2. No  
*Optional: If yes, explain or provide recommendation.*
2. Does the definition of this item need clarification? 1. Yes 2. No  
*Optional: If yes, explain or provide recommendation.*
3. Can this concept be used without any difficulty in your culture? 1. Yes 2. No  
*Optional: If it is not useful, please explain the problems in using the concept.*
4. Is this concept useful for all age groups in the culture? 1. Yes 2. No  
*Optional: If no, please explain which age groups it does not work for, and why.*
5. Is this concept useful for both genders? 1. Yes 2. No  
*Optional: If no, please explain.*
6. Is this concept useful for all social and economic groups in the culture? 1. Yes 2. No  
*Optional: If no, please explain whom it is not useful for, and why it is not useful.*
7. Is this concept useful for all of the ethnic or minority cultural groups in the society? 1. Yes 2. No  
*Optional: If no, please explain.*
8. Is this item culturally sensitive (difficult to talk about, taboo, embarrassing, etc.). 1. Yes 2. No  
*Optional: If yes, please explain.*
9. Is this item best placed in the classification as (circle one)?  
1. An impairment      2. An activity or disability      3. A participation issue
10. How important is it to keep this item in the ICDH-2 classification? (Circle answer)  
1                                  2                                  3                                  4  
not important                                  Very important

Figure 5. Paper and pencil data collection format for concept mapping

of the single page data collection format for the first item in the concept mapping is provided in the chart in Figure 5.

The sample specifications for the concept mapping were identical to those for the pile sorting (see above). In fact, sites were encouraged to use the same respondents for both exercises, and in most cases this was done. Where different respondents were used, a demographic face sheet was again filled out for each respondent.

### Concept mapping data analysis

These data allowed the researchers to apply several different types of statistical analysis to the items. They allowed the use of factor analysis to determine whether or not 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.

### Key informant interviews

The research 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 each key informant a series of open-ended questions. The second was to ask them to fill out a self-administered questionnaire. And the third was to ask the informants to complete a ranking exercise. At the start of the interview, the key informants were asked to describe what they thought was believed to be true in their culture, whether they agreed with it or not, to provide a consensual or normative frame for understanding the concepts being studied. A face sheet with demographic information was also completed for each key informant.

### Open-ended key informant questions

The first three open-ended questions were designed to cover the range of terms and concepts that exist in each local culture to describe disabilities and to cover the culture's view on disability:

1. What general word or words would people use to describe a situation where someone is NOT able to do things such as being unable to remember recent events, being unable to speak clearly, having a severe tremor,

or being without one leg, as a consequence of a health condition? That is, people would speak of them as... -what would you say? Any other words?

2. What general word or words would people use to describe a situation where a someone is NOT able to do things such as going shopping, looking after children, playing a game, or showing affection, as a consequence of a health condition? That is, people would speak of them as having... - what would you say? Any other words?
3. What general word or words would people use to describe a situation where someone is NOT able to take part in activities at the workplace, among family members, and in other social groups (e.g., friends or clubs), as a consequence of a health condition? That is, people would speak of them as having a - what would you say? Any other words?

### *Disability threshold identification scenarios*

The second set of questions presented four or five scenarios<sup>1</sup> and asked the key informants to respond to 10 semi-structured questions about each scenario. Each scenario described a health 'problems' that was said to caused difficulties with activities of everyday life. The purpose of the scenarios and questions was to explore the issue of thresholds of awareness of disability, thresholds of intervention, and issues of stigma and assistance for disabilities in the local culture. The five scenarios, to be translated into the local language, were as follows:

*Scenario 1 (Mobility).* Some people have difficulty walking or getting around unaided as the result of a health condition. Sometimes their difficulty with this is obvious, but sometimes it is not.

*Scenario 2 (Mental Disorder).* Some people have difficulty with the activities of everyday life because they are bothered by strange thoughts, and sometimes they cannot control their actions. Sometimes their difficulty with this is obvious, but sometimes it is not.

*Scenario 3 (Low intelligence).* Some people have difficulty with the activities of everyday life because they are bothered by strange thoughts, and sometimes they cannot control their actions. Sometimes their difficulty with this is obvious, but sometimes it is not.

*Scenario 4 (Alcohol problem).* Some people have difficulty with the activities of everyday life because of their drinking of alcoholic beverages.

They seem unable to control how much they drink. Sometimes the difficulty with this is obvious, but sometimes it is not.

*Scenario 5 (Heroin problem).* Some people have difficulty with the activities of everyday life because of their taking drugs. They seem unable to control the amount of drugs they take and how often they take the drugs. Sometimes the difficulty with this is obvious, but sometimes it is not.

Each scenario was presented to the key informant, and a set of questions was asked about the scenario. Then the second scenario was presented, and the same set of questions asked, until all scenarios had been investigated. The questions asked about each scenario were these:

- a. If someone had a problem like this, but it was quite mild, what aspects of the person's behavior might *first* attract the attention or notice of others, such as family members, neighbors or co-workers?
- b. What if the problem was fairly serious - what would people consider to be signs of that (i.e., a serious problem)?
- c. What would people consider to be signs that this person needed help from someone else with the activities of everyday life?
- d. How much do you think a fairly serious problem of this sort would affect the person's ability to get a job or do productive work?
- e. What about the ability to get married and have a family - how much would that be affected if the person had a fairly serious problem like this?
- f. Suppose a person with a serious problem like this felt that they should get social assistance from the government because of it. What would people feel should be the *minimum period* for which the problem should have existed before they can receive assistance?
- g. Would people around here think they should get this assistance if the problem was serious?  
Yes No It depends - on what? (please specify below)
- h. What types of problems do you think a person with a serious problem like this might experience in their daily activities? Any other problems?

*[Scenarios 1 & 2 only]* What about if their problem was something they had had from birth - would that affect how others thought of the problem and how the person was regarded? In what ways?

*[Scenarios 4 & 5 only]* What about if the problem was seen as the being the result of a death in the family - would that affect how others thought of the problem and how the person was regarded? In what ways?

*[Scenarios 1 & 2 only]* What about if the problem resulted from a road accident - would that affect how others thought of the problem and how the person was regarded? In what ways?

<sup>1</sup> The fifth scenario is a drug use scenario. This was added at the request of a National Institute on Drug Abuse representative to the Joint Project, after the field research had begun. Some of the sites had already completed their key informant interviews, at that time, and therefore there is no drug scenario data for those sites.

The centre principal investigators were asked to provide a qualitative summary in English of responses to these scenarios and to the first three questions (above), in a question-by-question summary of the responses from all the informants. The summaries were to include the full range of responses, and the most normative responses. Quotations that exemplified the most salient issues were requested for each question summary.

### *Ranking exercise method*

After the first portion of the key informant interview was completed, each informant was 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). Each person was asked to think of the most disabling condition as the one where the person with that condition would find carrying on the activities of daily life (such as eating a meal or getting around) difficult, and the least disabling would be that which would not interfere with these activities.

The 17 health conditions and descriptions were presented as follows:

Active psychosis:	Being unable to judge what is real such as having delusions (false firm beliefs), hearing voices, and being unable to speak in clear sentences;
Alcoholism:	Drinking excessively and 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;
Dementia:	Multiple cognitive deficits that include problems with memory mainly and in addition with language and with performing motor tasks in spite of no weakness or abnormalities of sensation;
Drug dependence:	Taking drugs excessively and being unable to control one's drug-taking, even though it causes problems in one's life;
HIV positive:	Being infected with the virus that causes AIDS, and may be fatal;
Incontinence:	Leaking of urine and/or faeces with the associated odour;
Infertility:	Being unable to have a child; assuming it is desired;

Major depression:	The loss of interest or pleasure in nearly all activities; decreased energy; feelings of worthlessness; difficulty in thinking, concentrating, and making decisions;
Mild mental Retardation:	An adult having a mental age range between 9 and 12 years; having lower than normal intelligence (say between 55%-70% of average adult intelligence);
Paraplegia:	The lower half of the body is paralysed, including both legs; assuming access to a basic wheelchair or similar device to assist mobility;
Quadriplegia:	Both legs and both arms are paralysed; assuming access to a basic wheelchair or similar device to assist mobility;
Rheumatoid arthritis:	Stiffness of small joints of the hand, more so during the early part of the day, associated with deformities;
Severe migraines:	Having continuous severe headaches for one year and often being bed-ridden as a result;
Total blindness:	Being unable to see at all;
Total deafness:	Being unable to hear at all;
Vitiligo on face:	Having at least 10% of the face afflicted with permanent depigmentation (white patches).

The rankings were collected on a data form for each of the Key Informants, along with a demographic face sheet and the open-ended question data.

### *Scenarios on cultural barriers and acceptance*

Key informants were then asked to fill out a self-administered questionnaire. The questionnaire consisted of two sections. In section 1, the key informant was presented with five scenarios, parallel to the ones in the semi-structured interview:

*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, such as personal grooming.

*Scenario 2.* Think of a person who was born with low intelligence. The person has a very sweet disposition, and can wash and go to the toilet without help, talk to and understand others, and get around alone. However, the person cannot count the amount of change from buying something, and has never learned to read well.

*Scenario 3.* Now think of a person who says there are voices talking to

him/her all the time. Sometimes the person goes up to strangers on the street and shouts things at them that do not make much sense.

*Scenario 4.* What about a person who can be found in the neighbourhood bar at just about any time of day or night, with a drink in hand. Sometimes the bartender has to wake the person when the bar closes.

*Scenario 5.* What about a person who can be found in the neighbourhood just about any time of day or night, quite clearly under the influence of drugs. Sometimes someone finds the person by the roadside and has to help the person home.

For each scenario, the informants were asked to check off precoded answers to two questions for each of 10 activities. For the first question, "How surprised would people be if this person did this activity?" the response categories ranged from "not at all surprised" to "a little surprised," "surprised," and "very surprised." For the second question, "Is it likely that anyone would place restrictions or barriers on the person doing this?" the response categories were "very unlikely (that there would be restrictions or barriers)," "somewhat unlikely," "somewhat likely," and "very likely." The 10 activities that were explored were all activities from ICDH-2, as follows:

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;
10. Being elected or named to a position in local government.

### *Social disapproval and reaction to public appearance*

Finally, in section 2 of the self-administered questionnaire informants were asked to fill out two matrices of questions. In the first, they were asked to indicate the degree of social disapproval and negative reaction - scored by 0 for no disapproval and 10 for an extreme level of disapproval - experienced by a person labelled as being, or having the condition of

Wheel chair bound  
Borderline intelligence

Alcoholism  
Drug addiction  
HIV positive  
Dementia  
Homeless  
Criminal record for burglary  
Depression  
Blindness  
Leprosy  
Chronic mental disorder  
Dirty and unkempt  
Inability to read  
Obese  
Someone who does not take care of their children  
Facial disfigurement  
Someone who cannot hold down a job

Finally, in the second matrix, informants were asked to indicate "how people in [your] society would think about the person with the condition appearing in public - for instance, in a store or market." Response choices for the 10 listed conditions were as follows:

- People would think there was no issue, and would pay no attention;
- People would notice, but would not think there was any issue;
- People would be uneasy about it, but would probably not do anything;
- People would be uneasy about it, and try to avoid the person;
- People would think it was wrong, and might say something about it;
- People would think it was wrong, and would try to stop it.

The conditions asked about were as follows:

- Someone with a chronic mental disorder who "acts out";
- A woman in her 8th month of pregnancy;
- A person in a wheelchair;
- A person who is intellectually "slow";
- Someone who is dirty and unkempt;
- Someone with a face disfigured from burns;
- An obese person;
- Someone who is visibly is under the influence of drugs;
- Someone who is blind.

### *Key informant sampling issues*

The research collaborators decided that the set of individuals interviewed for the key informant study should be different from the set interviewed in the pile sort and concept mapping study. A total of 15 individuals were to be chosen for the key informant interviews, divided into five subsamples. The individuals chosen for each subsample were to be as broadly representative of all of the viewpoints about disabilities as possible. The sample was to include three individuals who were medical professionals, three disability specialists, three with a disabling condition, three care-givers to persons with disabilities, and three policy makers or opinion leaders in the field of disability services.

### **Focus groups**

Each site was asked to conduct two out of three possible focus group studies. The first study option explored the underlying model of the ICIDH-2. The focus groups were conducted with health and social service professionals who would be involved in the use and dissemination of the ICIDH-2, and with persons with disabilities. The second study option explored the stigma attached to disabilities in each culture. These focus groups were conducted with groups of persons with disabilities, and with groups of family members of persons with disabilities. The third study option explored the current practices and needs related to disabilities. These focus groups were conducted with individuals who had experienced disabilities, members of families with such individuals, and health and social service professionals in disability service systems. The study explored the configuration of services that were available, those that were not available but perceived to be needed, and the conditions that had an impact on both the services and the need for services in the society. The focus group guides (questions and probes used at all sites) are available from WHO in Geneva. The basic issues covered in each of the focus groups are summarized below.

### *Focus group studies*

The focus group studies agreed upon by the research centres are as follows:

*Study 1: The model of the disablement process in the ICIDH-2.* The purpose of this effort was to provide a cross-cultural assessment of the concepts

and relationships used to create the structure of the ICIDH-2. The primary subject areas covered in the focus groups were: (1) an evaluation of the disablement process model proposed in the ICIDH-2 Beta 1; and (2) an exploration of the system used in the local culture to determine the presence and severity of disabilities. The discussion of disability thresholds, including discussions of the difference between classification of the presence or absence of disabilities, compared with systems that assign levels of disabilities (percentage disabled) formed a part of these focus groups.

*Study 2: Parity and stigmatization of disabilities.* This study permitted 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. Parity in the provision of health and other resources means that services and benefits are provided on the basis of need, rather than on whether the underlying health condition is physical, mental or an alcohol or drug abuse disorder. The aim of this study was to gather information about the degree to which parity is viewed as a good or desirable thing for society to achieve. The project was targeted at gaining information from college students as surrogates for the educated general public in each culture, and from family members of individuals who had disabilities. This provided the opportunity to add the viewpoint of family members and of the general population as a supplementary part of the overall cross-cultural assessment of disabilities. The sampling strategy also allowed general popular views to be contrasted with the views of family members of individuals with disabilities.

*Study 3: Current practices and needs.* The purpose of this study was to explore the range and variation in the services provided to persons with disabilities, and to identify similarities and differences in the perceived need for additional services, across cultures. The primary subject areas to be explored in each culture were: (1) a discussion of the existing laws and social programmes that provide assistance for individuals with disabilities; (2) the met and unmet needs for disability services, from the individual and family level to the societal level; and (3) current practices and needs associated with disabilities.

### *Sample size and resource commitment*

The requested effort for the focus group project was to conduct a minimum of two focus groups for each of two studies. Each focus group was to consist

of 6-8 persons. Each focus group study had slightly different requirements for the selection of participants, but in each case - as explained above - the participation was to include individuals who were experienced in disabilities (including persons with disabilities, care-givers, and where appropriate, health professionals). A face sheet with demographic information was completed for each person participating in a focus group.

### CAR study samples from centres

Each of the collaborating centres completed the core tasks for the CAR study, although some methods were not conducted at certain centres. Table 1 sets out the final data set summaries by research method, showing the overall number of centres, informants, respondents, or group sessions involved in each.

*Table 1.* Data-collection methods and numbers of centres, informants or data collection sessions

Method	Total number (all centres)
Centre descriptive	15 centres <sup>2</sup>
Translation and linguistic analysis	12 centres (3 used original English version)
Pile sorting	450 informants at 19 centres
Concept mapping	441 informants at 18 centres
Key informant interviews	230 informants at 18 centres
Focus groups	22 focus groups at 7 centres

### Discussion

The CAR suite of methods combines the collection of qualitative and quantitative data. Each method was targeted at resolving multiple questions or issues confronting the ICIDH-2 revision process and the development of cross-culturally applicable assessment instruments. The overall results, described in detail in later chapters, was very useful in the revision of the ICIDH, and valuable in the construction of ICIDH-2 related assessment instruments. The amount of data that was produced was enormous. The initial use of the data to inform the revision of the ICIDH-2 is also described below. The data from each research methods at each centre are presented separately in subsequent chapters. Anecdotal reports from each of the participating centres indicate that several of the methods produced unexpected learning opportunities, beyond the simple data collection. The pile sorting exercise was thought

<sup>2</sup> The centre report for Tunisia and Egypt were provided as a single report.

to be fun by many participants. It also provided interesting additional information about the classification, because of people's natural tendency to talk to themselves or to the interviewer while doing the pile sorting. The focus groups were particularly powerful in providing the centre researchers with insights into the public's and professionals' views of disabilities in their culture; people tend to engage in interactive dialogues in focus group situations and this provides emotive information, in addition to information about cultural values and beliefs.

By means of triangulation from different methodologies, the data sets provided a good convergent confirmation of many of the findings. In combination, the linguistic analysis, pile sorting data and the concept mapping data identified the items in the classification that are the most stable across cultures, and those items that are the most problematic. These findings have been taken into account in the subsequent development of instruments. The triangulation also identified the boundary areas between the three dimensions of the classification, and the items that needed improvement in order to move from a stable to a highly stable status within the system.

In summary, this combination of ethnographic, rapid assessment, and statistical methods has produced the results needed at each stage of the ICIDH revision process. The methods promise to continue to provide valuable recommendations, interpretations, and innovative directions throughout the revision process to the final adoption of the revised ICIDH-2 by the World Health Assembly.

### Appendix A. Linguistic analysis protocol

#### List A

Disease  
Disorder  
Health Condition  
Impairment  
Disability  
Disablement  
Handicap  
Participation  
Environment  
Context  
Consequence  
Ability  
Activity  
Integrity

Structure  
 Function  
 Interference  
 Well-being  
 Quality of life  
 Community  
 Society  
 Mobility  
 Memory  
 Attention  
 Thought, abstraction, judgement, and related executive functions  
 Leisure and leisure activities  
 Economicself-sufficiency  
 Non-verbal communication  
 Perception  
 Civic and community life  
 Tolerance in relationship  
 Organizing daily routine  
 Temperament and personality  
 Orientation  
 Self-care  
 Consciousness  
 Expressing empathy  
 Problem solving  
 Use of humor  
 Affect  
 Interpersonal and social relationship  
 Managing close personal relationships  
 Handling everyday physical environment  
 Citizenship responsibilities

### List B

ID	Item	Phrases
1	Transferring oneself	Everyday I transfer myself from my bed to my wheelchair.
2	Seeing	I have no trouble seeing the screen in a movie theatre.
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.
5	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.

7	Interacting with an equal/co-worker/peer	The atmosphere at my place of work is wonderful, the interactions between peers and co-workers are cooperative, generally fruitful and pleasant.
8	Recognizing directions in space and time	I have no difficulty recognizing directions in space and time, I always know where I am going even in foreign cities and I have a very good notion of the sequence and occurrence of events.
9	Keeping appropriate physical contact, and maintenance of social space	I wish other people would keep to appropriate physical contact, I don't being touched by others even if they are just trying to be friendly. I also don't like people getting too close to me, I like to maintain my social space.
10	Understanding specific signs	I have no problem understanding specific signs when looking for the toilet in a restaurant or other public place.
11	Visual sensory functions	I use my visual sensory functions to see things that are near and far clearly.
12	Use of communication devices	I feel very uncomfortable using communication devices like the telephone.
13	Keeping self clean and appropriately groomed	It is pleasant to begin the day having washed, feeling fresh, and keeping oneself clean and appropriately groomed.
14	Hearing	I have no difficulty hearing somebody call my name from the next room.
15	Hearing functions	My hearing functions are not good enough to be able to hear soft sounds or whispers.
16	Taking care of one's health	I take care of my health by having regular medical check ups and following what my doctor tells me to do.
17	Eating and drinking	I like eating and drinking tasty food and drinks at banquets.
18	Maintaining physical environment	It is important to maintain one's physical environment clean in order to prevent illness.
19	Managing a dangerous environment	I am quite good at managing dangerous environments, I was caught in a fire once and managed to remain calm and follow instructions.
20	Arithmetic activities	I am not very good at arithmetic activities, I have difficulty adding, subtracting, multiplying and dividing without a calculator.
21	Managing relationships with friends	Managing relationships with friends requires you to keep in touch with them and share certain parts of your life and activities.
22	Motor coordination	Your motor coordination needs to be excellent if you have to be able to play the drums.
23	Performing an activity for an extended period (psychological endurance)	I usually get very restless and distracted while performing an activity for an extended period.

24	Intellectual development and function	It is important to engage children in constructive activities for their intellectual development and function.
25	Moving around	I need to move around in the house to be able to reach the things I need.
26	Work	One needs to work in order to make a living.
27	People sharing living space	My wife and son are the people who are sharing my living space in my house.
28	Following written instructions	I have no difficulty following the written instructions that my teachers give in class.
29	Planning/organizing meals	I feel overwhelmed when I'm required to plan and organize meals as it involves coordinating shopping cooking and serving the meal.
30	Cultural activities	I enjoy cultural activities such as festivals, theater, opera etc.
31	Handling technical devices/aids for locomotion	People need to be trained at handling technical devices for locomotion such as wheelchairs to give them more freedom of movement.
32	Communication activities	When I trained to be a teacher I had to take courses in communication activities.
33	Changing a body position	For people who are completely paralyzed it can be difficult changing a body position.
34	Following (showing interest in) events that take place outside of the direct environment	I follow events that take place outside of the direct environment by watching the news on TV and reading the newspaper.
35	Study behaviours	My study behaviours change depending on how much the subject interests me.
36	Recognizing	When I cross a friend on the street who I recognize I usually greet him.
37	Written communication	Written communication such as letters are very important for business transactions.
38	Managing general psychological demands	I have difficulties managing general psychological demands at times and feel under pressure and stress.
39	Taking care of pets/domestic animals	I take care of my pet cat by feeding it regularly, allowing it to exercise and taking it to the doctor for its regular check ups.
40	Communication content	I should pay attention, while speaking to people, not only about the communication content but also how I say things.
41	Activities related to fulfilling of financial obligations and services	I always fulfill my financial obligations, all my taxes and bills are always paid on time.
42	Maintaining a body position	I have difficulty maintaining a body position for a length of time, after a few minutes I get restless and I feel like moving around.

43	Cooking, baking, frying solids	When cooking baking and frying solid foods, one must be careful not to overcook or burn it.
44	Conversation processes and structure	When we speak to each other, our interactions are shaped by the conversation processes and structure.
45	Abilities relating to learning and communication	Reading, writing, arithmetic, giving and taking messages build the foundations for our abilities relating to learning and communication.
46	Taking care of meals	Taking care of meals involves shopping, as well as cooking and preparing meals.
47	Dating and forming relationship	Some people have trouble dating and forming relationships because they are too shy to open up to the person they are attracted to.
48	Energy and drive	My energy and drive is what keeps me from starving, otherwise I would forget to eat.
49	Religious activities	Traditional religious activities are a time to bring families and communities with common beliefs together.
50	Psychomotor activity	When one is depressed one feels slowed down and one's psychomotor activity is decreased.
51	Handling body attached technical aids	It is really remarkable what people can really do once they have become good at handling body attached technical aids such as calipers and artificial limbs.
52	Keeping rules, abiding by decisions	Sometimes, children have difficulty keeping rules or abiding by decisions, they tend to be disobedient and rebellious.
53	Sexual functions	Sex education for adolescents is aimed at making them more aware and in touch with their sexual functions.
54	Washing oneself	I like to wash myself every morning, so that I feel clean and fresh.
55	Following verbal instructions	Following verbal instructions over the telephone can be difficult if I am not familiar with the subject matter.
56	Education	Good education helps a person to learn well and lays a good foundation for the future.
57	Language	Using foul language is something people do when upset or angry.
58	Work acquisition and retention behaviours	To succeed in one's career it is important to have the right kind of work acquisition and retention behaviours.
59	Performing consensual sexual acts	The right approach and care in performing consensual sexual acts is important for a healthy relationship.
60	Procurement and care of necessities	Persons who have a low intelligence may need help in the procurement and care of necessities of everyday life.

61	Responding to conversational cues	Responding to conversational cues is necessary to maintain an interesting conversation.
62	Taking care of household or family members	Much of my time as a housewife is spent taking care of the household or family members.
63	Monitoring and evaluating of performance of activities, tasks	Monitoring and evaluating the performance of activities and tasks helps us learn from our mistakes and do better next time.
64	Managing personal behaviour	In my relations with others I am generally careful in managing my personal behaviour and keep my mood and impulses under check.
65	Using public transport	Using public transport such as buses (or trains) can be quite a challenge at rush hour.
66	Responding to dangers	Children and old people need looking after as they may not be quick in responding to dangers.
67	Illness	I told the doctor that I caught this illness while I was travelling.