Chapter 2

Objectives and Overall Plan for the ICIDH-2 Cross-Cultural Applicability Research Study

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Background

The cross-cultural applicability research study (CAR) for ICIDH-2 revision and instrument development was conducted as an early part of a multi-year joint project between the World Health Organization (WHO), the US National Institutes of Health (NIH), and participating centres around the world. The overall aim of the project was to develop disability assessment instruments, based on a revision of the *International Classification of Impairments, Disabilities and Handicaps* (ICIDH 1980) that would be applicable in different cultures. These instruments will subsequently be used in epidemiological research, to determine the nature and extent of disabilities world-wide. They will be used in health services research to discover better ways to provide effective services to disabled persons. They will also be used in prevention and intervention research projects to assess changes in the levels of disability in various communities, where local, regional and national prevention programmes are being tested for effectiveness. The CAR study formed the basis for assuring that the revised ICIDH-2 concepts, and the instruments, could be used to compare international disability statistics correctly and in planning comparable and effective health services around the world.

The WHO team and participating centres have all had extensive experience working with cross-cultural health issues, instrument development, and health classifications. WHO researchers determined that there were two critical requirements for the CAR research. First, it had to provide data on the cultural comparability of the disability construct, the basic theory and philosophy behind the international understanding of disabilities and health proc-

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esses. Secondly, the CAR data needed to guarantee that the psychometric properties (in particular, statistical stability, usefulness, reliability, and validity) of the instruments were correctly developed in relation to the best standards for cross-cultural and multinational research instruments. These were the minimum conditions necessary to obtain valid cross-cultural comparisons of disabilities.

Cross-cultural applicability also required the creation of classification items and instruments that met the three dimensions of equivalence mentioned in Chapter 1, namely functional, conceptual and metric equivalence. Achieving these equivalences for all elements of the classification and all items of the cross-cultural instruments is the ideal. The principal focus of the CAR research for disabilities was to provide the preliminary groundwork to meet these equivalence requirements; its purpose, therefore, was to explore the consistency of the disability construct in different cultures.

Disability assessment across cultures requires that the disablement process be conceived as a common phenomenon in different cultural settings, languages, and value systems. Investigating these conditions also includes examining the comparable anchor points or thresholds for common manifestations (e.g., the kinds or degrees of disability that make people eligible to take a day off, or the criteria for early retirement or inability to work). Because different societies have different levels of resources available for disability programmes, they often put the thresholds for assistance to disabled people at different levels, and for this reason it was important to determine if the process of assessment, and the goals for using a global measure of disability are comparable or compatible across cultures. The WHO team and the centre experts agreed that the identification of a common basis for such assessment, scales, and probing styles would clearly assist the construction of cross-culturally valid instruments.

An earlier phase of the WHO-NIH joint project (1980-1996) looked at the diagnosis and classification of mental and related disorders. During that project, a set of qualitative methods was tested to assist with cross-cultural applicability research attached to that phase of the project. These methods included linguistic analysis, key informant interviews, focus groups, expert opinion surveys, and reference case studies. The methods helped to explore the consistency of the conceptualization of mental and related disorders across cultures. They explored such issues as how the dependence syndrome was conceived, whether the concept of "narrowing of repertoire" was applicable in different cultures, and how the basic alcohol and drug dependence criteria could be compared across cultures (Room, Janca, Bennett et al. 1996).

The WHO team and centre experts felt that similar lines of research activities would be useful in order to identify the cross-cultural similarities and differences in the concepts underlying the classification and assessment of disabilities. The CAR study was therefore designed to identify the cultural constancy of the disability construct, and to provide information that would assist in developing culturally applicable assessment instruments, such as surveys, check-lists, and screening questionnaires. The CAR model responded to the need to compare how different cultures conceived of, and spoke about, what people cannot do as a consequence of their health conditions. It also met the need to explore disability anchor points or thresholds for common manifestations of problems.

Reviews of classifications, instruments and the scientific literature suggested that there was a significant lack of parity between the acknowledgement and treatment of physical disabilities, compared with disabilities that were the consequence of or were associated with alcohol, drug abuse, and mental health disorders. Therefore, with funding support from the US National Institutes of Health (NIAAA, NIDA, NIMH), one particular aim of the CAR study was to assess the cross-cultural applicability of ADM disorder-related disabilities. This required the addition of cross-cultural applicability methods that would help to generate and test an instrument item pool, check for missing classification categories and additional concepts, and conduct an overall assessment of mental health and physical categories, domains, and thresholds.

The CAR study protocols were designed to accomplish six goals simultaneously:

1. Understand the current needs and practices of institutions in different cultures that are involved in the assessment or care of people with both physical and ADM disabilities or are involved in working with these populations, including the implications for social security and the law;
2. Explore and describe the cross culturally stable and cross culturally divergent views of disabilities, in terms of stigma attached to disabilities, parity between ADM and physical disabilities, cultural values associated with disabilities, and the forms of support and assistance that are available in various cultures;
3. Determine whether the ICIDH-2 disability domains and items are generally applicable and whether identical or similar concepts exist in each local culture;
4. Determine whether each domain and item was culturally appropriate, in terms of the cultural sensitivity of the item;
5. Determine whether these terms can be translated into the local language or need to be modified, either in the original English, or in the local language;

6. Determine whether the domains and items are applicable across age groups, genders, socio-economic statuses, occupations, professional groups, and service agencies.

In addition, each disability item in the classification needed to be assessed in terms of its terminological and definitional clarity, and its usefulness in the classification.

The CAR study also looked at the coverage of the overall universe of disabilities, and the appropriateness of placing the item in the impairment, activity limitation or participation restriction sections of the classification. This required the use of several classification assessment tools within the CAR study. There were a number of assessment needs that focused on the operationalization of the assessment categories required to develop the ICIDH-2 related instruments. These assessment requirements included:

1. The need for cross-culturally applicability of definitions of the terms to ensure that they are consistently applicable, and quantifiable, across cultures and languages;
2. The availability of anchors that would determine severity and identify common points of contact, such as subjective distress and whether the dysfunctioning is noticed by the person, significant others, or society at large;
3. Identifying the presence of thresholds beyond which people are considered to have a disability;
4. Identifying the presence of positive and negative attitudes, as well as available social supports, in different cultures;
5. Identifying the presence, or lack of parity between the different types of disabilities;
6. The need to transform operational criteria into an interview that could then be tested for appropriateness and comparability across settings;
7. The feasibility and applicability of measuring performance cross-culturally, either within actual settings such as work or the household, or else in a laboratory setting.

This is a significant burden to place on a study. However, the prior cross-cultural applicability studies and advances in qualitative research techniques indicated that all of these requirements and goals could be accomplished with a relatively compact set of research methods. Similar methods have been used in cross-cultural research done by WHO in other projects, a number of which are related to mental health, substance abuse and quality of life (Coriel, Augustin, Holt et al. 1992; WHO 1994; WHOQOL Group, 1995; Room, Janca, Bennett et al. 1996). Thus each of the methods drawn from these examples, together with newly developed methods, provided critical information on one or more of the issues being investigated and at least double coverage of all the goals and requirements. In most cases they provided full triangulation on the issues.

Selection of research methods

It was obvious at the outset that no single research method could provide answers to all the questions that were relevant to the aims of the WHO-NIH joint project. Considerable effort was made to select a battery of methods that would be feasible in the various research centres and would be able to meet the required goals and standards without placing an undue burden on the centres.

The choice of research methods was influenced by other practical considerations. The decisions set some important limits on the CAR study. The timetable for the study was more restricted than is the normal case for qualitative research. If the research findings were to be useful in the parallel processes of drafting and revising the classification and developing assessment instruments related to the classification, then results from the study had to be available in a matter of months. The amount of work that could reasonably be asked of the study teams at each site was also limited. Only very modest resources were available from central funds for each site, so that most of the data collection was performed with national resources available within each investigator's institution or from local sources and in kind contributions. This constrained the number of data collection methods that could be used, and the number of cases that could be interviewed or studied by each method. Therefore the methods that were chosen had to be very robust, permitting small samples and ethnographic sampling procedures rather than probabilistic sampling designs.

The CAR study goals required that the ICIDH-2 concepts and items work in a number of different languages, but at the end of the study they had to be analysed across centres and described in a single language, since English has been the working language for the revision process and the development of assessment instruments. In such a situation, it is much more efficient to use preceded responses wherever possible, rather than demand the very substantial task of translation and summarization required by open-ended, qualitative responses and similar data. In recognition of this practical issue, precoded responses to questions were used whenever possible. This entailed some loss of depth and nuance in the study material, but made it more efficient and provided greater detail for the comparative analyses. At the same time, the centres managed to provide a great deal of in-depth qualitative data and interpretation in their summaries. This significantly supplemented the preceded data and gave a better understanding of local nuances and conditions.

The following types of methods were chosen for the CAR study, based on a number of general theoretical considerations and on the practical considerations described above.

Key informant interview

Ethnographic and other qualitative research traditions have depended heavily on interviews with cultural experts who can describe, evaluate, reflect upon, and summarize key aspects of their own culture. These individuals, called key informants, provide the basic knowledge that is necessary to understand the culture being studied. Thus, qualitative research projects rely on being able to select and interview an ethnographically representative sample of key cultural consultants (Bernard 1995). This type of informant provides information that is not available from individuals who are outsiders to a particular aspect of the cultural core, or who do not have the knowledge and experience to be able to discuss clearly those elements of the culture.

As the term "key informant" implies, the evidentiary status of the information gathered is inherently different in this method from experimental or questionnaire studies where the data are gathered from a "subject." In the informant mode, in principle the data are not a matter of personal attitudes or individual characteristics; instead, the informant is giving a considered opinion on what is true in the culture or in his or her social milieu. The data are thus primarily attributes of a collective, not of an individual respondent.

Use of respondents as informants is also common in quantitative research. When a survey research respondent is asked questions in the form "What do people around here think about________(an issue)," or "What proportion of your friends do_____(a behaviour)?" the answers represent the respondent's best effort to characterize a collective, rather than give a personal opinion. Thus, although it is not often discussed as such, there is a precedent for research in the informant mode in quantitative studies, using preceded responses. In the context of the present study, both open-ended qualitative information and precoded and quantifiable responses were collected from key informants. The criteria for choosing these individuals emphasized that the key informants should have knowledge in depth in a particular area of culture: informants were chosen because they were judged to be knowledgeable about aspects of the cultural conceptualizations and handling of disability concepts.

Focus group interview

Focus group interviews were chosen as part of the study's methodological mixture to provide the individual sites, and the group as a whole with an opportunity to explore collective views about particular cultural conditions. Focus groups are the commonest form of group interview utilized in qualitative research. They are a means of obtaining a considerable quantity of data in a relatively short period, from a larger number of people than would be possible with the same number of individual key informant interviews (Krueger 1994). They have been used in qualitative research for some time to study knowledge, attitudes and beliefs in a variety of social situations. They have advantages over individual interviews in that they allow the researcher to record and analyse people's reactions to ideas and to each other. The hallmark of focus groups is the "explicit use of the group interaction to produce data and insights that would be less accessible without the interaction found in a group" (Morgan 1997). Focus groups are normally lively and create back-and-forth discussion among the participants, based on topics and broad questions supplied by the researcher. They have the disadvantage of providing information primarily on subjects that people are willing to discuss in public, so that some parts of intimate subjects may be avoided or modified from actual beliefs and reported behavioural patterns when they are being discussed in the group.

Focus group interviews tend to produce very good "natural language discourse" that allows the researcher to learn the communication patterns in the community, as well as the key linguistic properties of the area under discussion. This process is very useful in exploring the "language of disabilities" at the broad societal level, while also investigating specific language and conceptual elements of the classification system. It also provided an opportunity for each of the centres to learn a great deal about public attitudes and beliefs about disabilities, in a short space of time, in parallel with the other forms of data collection that were informing the study.

Structured data collection: concept mapping and pile sorting

A number of systematic data collection techniques have been developed in the past few years that have proved extremely useful in qualitative research projects (Trotter 1991; Weller & Romney 1988). These approaches utilize an integrated set of mid-range anthropological theories to describe the cultural models of health and illness that provide a framework for understanding knowledge of and beliefs about health and behaviour. Some of the techniques identify the key social contexts in which beliefs and values are turned into action, while others establish the intervening conditions that either allow for change (protective forces) or prevent change (barriers) in risk behaviours. All of them provide a theoretical framework for determining decision-making and sustainable actions for cultural belief systems, and they identify the key symbolic and communication conditions imposed by cultural systems that relate to health behaviour and behavioural change.

The approaches developed by Kleinman (1980) and by Quinn and Holland (1987), among others, provide an excellent starting point for cross-cultural and within-culture research on health definitions and models of disease processes, and for establishing the basic conditions that humans recognize for identifying, treating, and understanding the consequences of health problems. These are the most qualitative processes, and the methods associated with these research designs include systematically administered semi-structured open-ended (qualitative or ethnographic) interviews analysed through hierarchical coding and pattern recognition of themes and conceptual linkages.

More targeted systematic explorations of mental health and other illness domains can subsequently be pursued through the use of three interlocked cognitive anthropology methods. These are techniques for exploring the content and limit of cultural domains (e.g., free listings, sentence frame completion, contrast sets), techniques for establishing the structural and cognitive relationships of the elements of cultural domains (e.g., pile sorts, dyad and triad tests, Q sorting, matrix profile analysis), and techniques for establishing the cultural consensual framework for these knowledge and belief systems (Weller & Romney 1988; Trotter 1991, 1995). Many of these techniques provide an excellent format for systematic ethnographic rapid assessment. They also provide a methodological basis for bridging between ethnographic and survey or experimental research designs, since they are typically analysed using both qualitative (description of meaning) and quantitative (cluster analysis, multidimensional scaling, correspondence analysis) analytical techniques.

The structured data collection methods used in the CAR study - concept mapping and pile sorting - approach the two methodological questions (who should provide the information that forms the basis for the data analysis? and what are the most appropriate techniques to collect these data?) from a perspective that complements the other methods used in the study. These techniques permitted a thorough cross-cultural exploration of the disability questions tackled in the study, utilizing statistical algorithms for analysis.

Concept mapping is a technique that allows researchers to explore single items within a larger conceptual framework, while also exploring the structure and relationships among the elements of that conceptual domain (Al-

Kunifed & Wandersee 1990; Adamczyk 1994; Domin 1996). It has been shown to be an excellent linkage mechanism between qualitative and quantitative approaches (Raymond 1997; Wiener, Wiley & Huelsman 1994). It has primarily been used in educational evaluation, including medical education (Edmondson 1995), but has also demonstrated power in evaluating medical model transference (Shern, Trochim & La Comb 1995), assessment of clinical programs (Trochim, Cook & Setze 1994; Holmes, Splaine &Teresi 1994), and policy studies (Lord, Desforges & Fein 1994).

Concept mapping is a useful strategy for revealing how people think about concepts since it requires a person to reflect and cognitively map out the territory of a concept, and in particular to think about overlaps and boundaries. If this map can be well understood and compared cross-culturally it can be invaluable in structuring a classification that is close to the way that people think about the territory. This helps to minimize misunderstanding and the misuse of the classification. Also it would help to identify potential areas of confusion so that efforts could be focused on further refining and differentiating those concepts.

The pile sorting technique used in the CAR study is descended from a well-established family of techniques used in psychological studies for testing subjects' clustering of items and concepts (Arabic, Hubert & De Soete 1997; Coxon 1999). For the particular technique used in this study, we sought to minimize the constraints imposed on the informant and to allow the maximum play for cultural and personal variation. As a result, the number of items that could be placed in a sort was not constrained, and a "residual" category was allowed, instead forcing the informant to sort all items into substantively meaningful piles.

The pile sorting technique allows us to see how natural groupings of concepts are made by people. This is important because it indicates the heuristic value of the classification principles in operation within the classification system. In other words, it shows the face validity of the abstract scientific principles used during the formulation of the classification. As an adjunct to concept mapping, it engages people in thinking about the concepts in a manner that can be very valuable in the design of assessment instruments for disability.

Linguistic analysis and translation and back-translation

Many of the theoretical positions utilized in the CAR study depend on explorations of communication and symbolic interaction both for their analysis and for associated research methods. Some of the current mid-range theories from ethnographic linguistics[1] include the theory that grammatical categories are the primary mechanism influencing culturally specific thought patterns (Lucy 1985); the position that meaning is only emergent and negotiated in interaction and cannot be reduced to individual intent or to grammatical categories (Verschueren 1995); the view that meaning is constructed through a metalanguage structure ("mentalese") that is an evolutionary by-product overshadowing the meanings constructed by any particular oral or written language that we might use (Pinker 1994); the proposition that methods for "unpacking" the constituent "footings" or "voices" present in speaker's roles are critical to understanding communication in context, in opposition to the reduction of communication patterns to speaker/sender and receiver/hearer constructions (Trawick 1988); and the theory that speech creates social context and cannot be separated from the notions of "context," "class," and "identity" sufficiently to justify reifying those notions as separate from speech (Goodwin & Duranti 1992).

The ICIDH-2 classification has faced a number of challenges because of the need to translate it into many very different languages, with full correspondence of the items and complete conceptual transfer. It has become a WHO standard to build a translation/back-translation protocol into the development and revision processes of its family of classifications. Examples come from psychiatry and work on the ICD-10 (Sartorius 1976). The need for a common language and agreed upon usage of terms in these classifications is well established (Sartorius, Kaelber, Cooper et al. 1993). In a refinement of the earlier linguistic protocols, the protocol used for ICIDH-2 was designed to produce three types of equivalence between translations: semantic equivalence of denotation and connotation of terms; conceptual equivalence of the position and significance of the salient concepts, in relation to the theoretical model; and technical equivalence in the way each item is used to obtain information, that is, the validity and reliability of the item across linguistic boundaries.

The linguistic analysis of domains and items was intended to examine and understand how each culture thinks about disability. The focus was not so much on the literal translatability of the terms as on an examination of the role played by the concepts in the different cultures and the nuances in the meaning of these terms. This information is the first important step in determining the semantic and conceptual equivalence of terms and is critical for communication between professionals internationally, and for initiating a dialogue within the culture about disability. This process provides valuable insights into designing assessment interviews, survey methods, advocacy strategies and so on.

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[1] We thank Dr. James Wilce, Department of Anthropology, Northern Arizona University, USA for a review of mid-range theories that are being applied in linguistic medical anthropology.

In addition to these methods, a description of the disability process in the different cultures was also obtained from each of the centres. It was solicited by means of an open-ended questionnaire that provided information on the individual settings in which the study was being carried out (in the form of a thumbnail sketch of the disability scenario in each culture). It provided the backdrop against which to interpret the results of the study and was a starting point to help identify areas for intervention or change.

Specific aims of the methods used

There were 12 specific aims of the CAR study derived from the specific data needed to complete the ICIDH-2 revision process successfully and to develop internationally stable disability assessment instruments. The data were designed not only to describe the local cultural conditions, but also to allow a comparison of these conditions across cultures. The needs were:

1. To create a general description of the place and meaning of disabilities and disability programmes in local cultures;
2. To summarise informants' descriptions of the current programmes, and need for programmes, that serve populations with disabilities;
3. To explore cultural contexts, practices, and values concerning disabilities,
4. To establish information on the thresholds that determine when, in a particular culture, a person is considered disabled;
5. To compare the relative importance of different types of disabling conditions in different cultures;
6. To collect data on the parity or lack of parity between mental health, alcohol and drug problems, and physical health problems;
7. To gather information on stigma attached to various types of disabilities;
8. To explore alternative conceptual models for the classification;
9. To identify linguistic equivalences for conceptual transfer of elements of the classification into local languages, and back to English;
10. To determine whether the proposed structure of the classification has good cross-cultural stability;
11. To provide an item-by-item evaluation of the cross-cultural applicability of each facet of the classification; and
12. To collect data on the boundaries between the three domains of the classification system.

The methods chosen for the study were also designed to help to investigate information on the cultural sensitivity attached to various types of disabilities. The issue of how to ask about disabilities that have an impact on individuals' sexual activities was consistently the most difficult to approach within cultures, followed by other topics that were considered intimate (some family relationships, politics in some cultures, and alcohol-and-drug-related issues in other cultures). The methods were also designed to help to compare the relative importance of different types of disabling conditions in different cultures. Both issues were explored at the general cultural level, through focus groups and key informant interviews that allowed members of the culture to indicate areas of the culture that would be difficult to explore through assessment interviews. They were then explored at the specific item, term or concept level through the pile sorting and concept mapping data collection processes.

Triangulation of aims, methods, and analytical coverage

The cross-cultural methods used in the CAR study were selected to allow empirical testing of how well the elements of the proposed revised classification could address the primary project aims and how well they could provide an analysis that covered all of the different data needs from the perspective of two or more analytical strategies. Table 1 identifies the match between each method chosen and the 12 aims. The selected methods not only cover the needs, but also allow significant triangulation of results, without unnecessary duplication.

Table 1. The ICIDH-2 CAR model: matching methods with data needs

Research Methods *(Types of data collected)*	**Research Issues for Project**	**12 Data Needs by Method**
Centre description information *(qualitative)*	Current practices and needs for disability services; policy information on disabilities; values and cultural responses to disabilities; legal status of disability assistance.	(1) General description of the meaning of disability; (2) description of the current programmes; (3) cultural contexts, practices and values concerning disability; (6) parity or lack of parity; (8) exploring alternative models; (9) identifying linguistic equivalences for conceptual transfer.
Translation/back-translation and linguistic analysis protocols *(qualitative)*	Linguistic equivalences for items or sections off the classification; identification of problematic individual items.	(9) Identifying linguistic equivalences for conceptual transfer.
Pilesorting *(qualitative and quantitative)*	Cross-cultural stability of the classification; identification of problematic individual items; discovery of underlying cultural dimensions within the classification.	(10) Investigating proposed structure of the classification; (11) item-by-item evaluation of cross-cultural applicability.
Concept mapping *(quantitative, some qualitative)*	Cultural applicability of items; problems with taboo; age and gender bias; socioeconomic conditions; linguistic problems with items.	(3) Cultural contexts, practices and values concerning disabilities; (10) investigating proposed structure of the classification; (11) item-by-item evaluation of cross-cultural applicability; (12) data on the boundaries of the classification system.
Key informant interviews *(qualitative, ranking)*	Cultural contexts, practices and values relating to disabilities; perceived relative severity of different disabling conditions; comparison between different disabling conditions.	(3) Cultural contexts, practices and values concerning disabilities; (4) thresholds of disabilities; (5) relative importance of different types of disabling conditions in different cultures; (6) parity or lack of parity; (7) stigma attached to various types of disabilities.
Focus Groups *(qualitative)*	Conceptual integrity of ICIDH-2 model, and suggestions for modifications; exploration of current practices and needs; parity between mental, physical and drug and alcohol use-related disabilities.	

Selection of study sites

Once the methods were chosen, it became important to select a set of collaborating centres that could successfully carry out the study. A careful choice of study sites is extremely important for the success of this type of project. The standard approach requires and greatly benefits from the inclusion of developing as well as developed countries, together with the broadest cultural, linguistic, and geographical representation possible. The sites for the CAR study were chosen to provide the maximum comparability and contrast of language, culture, geography, and institutionalization of disability services.

In the final selection of the sites, the diversity of culture, language, environment, and health services was considered, as well as whether the centre had previous experience in the assessment and classification of ADM disorders and disabilities as well as familiarity with qualitative and quantitative research methods. The selection also took into account whether the centre was willing to participate, ready to take part in international research, and capable of carrying out the basic requirements of the protocol. Many of the centres chosen to participate had been involved in the first phase of the WHO-NIH joint project on the diagnosis and classification of mental disorders, which meant that they also had a history of working together in collaboration on this type of project and were experienced in exchanging in-depth cross-cultural information and viewpoints. A number of other sites were freshly recruited for this study and added substantively to the mix of languages, cultures, and viewpoints about disabilities. Almost all of the sites did all, or nearly all of the six protocols, although the option focus group method was only fully accomplished by 6 of the 15 sites.

Another strategy to make the research methods better suited to the aims of the study was to involve the field trial centres during the planning stage of the study. This was achieved by inviting a number of centre investigators to attend planning meetings and conducting informal discussions with them so that each centre saw that the demands of the study were both relevant and feasible. This process also helped to establish a close working relationship between the co-ordinating team and the centre investigators and to ensure continued cooperation during the conduct of the fieldwork.

Sampling issues

The sample selection processes for the CAR study were designed to address a constant problem for multisite cross-cultural research. The research requires a standardized sampling framework that does not place an extreme burden on the various centres. It must also accommodate the need to have comparable cross-cultural samples, and sample sizes that allow both within-site and cross-site analysis of data collected by each method. We used an ethnographic sampling approach, selecting individuals who were especially knowledgeable about their culture, instead of randomly selecting individuals who might not be able to contribute substantively to the study. The sampling procedures used are described in detail in *Selecting Ethnographic Informants* (Johnson 1990). Their selection was based on the success of earlier WHO projects. They are appropriate for combined qualitative and quantitative research designs (Trotter & Schensul 1998; Morgan 1997).

The study design required selecting a broad range of people with excellent and extensive knowledge of disabilities, since the cross-cultural applicability research was focused on well-defined conditions that need exploration in terms of specific beliefs and behaviours. The general approach followed in the CAR utilized targeted purposive sampling (Kaplan, Korf, Sterk 1987). This technique allows the researcher to build strategically a sample of individuals sharing one common characteristic - such as their health condition - within a large universe of individuals who may or may not share this attribute. Goodman (1961) originally formulated the method; van Meter (1990) and Johnson, Boster and Holbert (1989) provided an important assessment of the representativeness of these samples for populations; and finally, Patrick, Pruchno and Rose (1998) compared the costs and effectiveness of purposive sampling compared to four other sampling approaches. Since the CAR study sought to collect information on the culture's understanding of the disablement process and the societal responses to it, selection of informants was crucial for the success of the study. As mentioned, this type of prototypical sampling was designed to differ from classical probabilistic sampling in that the informants selected were expected to be spokespersons for their culture and knowledgeable about disabilities as seen in their culture.

The following groups were required to be included in samples and subsamples for the different methods utilized by the CAR study, at the various sites:

- Persons with disabilities;
- Informal care providers for persons with disabilities (family members);
- Professional care providers for persons with disabilities (doctors, nurses, occupational therapists, social workers);
- Disability experts;
- Policy-makers or opinion leaders in the area of disabilities.

While any individual informant was considered to be potentially familiar with at least one type of disability, the design was set up to ensure that the overall sample at each site was familiar with disabilities associated with physical, mental, and alcohol- and drug-related health conditions. Thus the aggregate information derived from each site would fulfil the objectives of the study, and also allow cross-site comparisons by health condition type. Since many of the sites had been working in this area for a long time, they were able to draw on their network of resources to select appropriate informants. In-depth information on the methodological approaches and the sampling design for the CAR project is provided in the following chapter. The confluence of theory, methods, outstanding research sites, and the basic questions proposed for the study all provided an excellent platform for conducting the study.