

## Chapter 19

# Cross-Cultural Views on Stigma, Valuation, Parity, and Societal Values Towards Disability

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The CAR study was designed to provide empirical data on the concept of disability, the cross-cultural elements of disability terms, and cultural values concerning disabilities. The study also covered within-culture approaches to assistance, the relative stigma associated with different disabilities, and the extent to which there is parity in the ways that cultures approach disabilities associated with different kinds of health conditions - physical, mental, and alcohol or drug-related.

The CAR study protocol was partially or completely conducted at 16 participating centres. The centres collected both qualitative data and preceded information to provide extensive data on the cultural relativity of the disability construct and on the categories that form the backbone of the ICDH-2 revised classification, and of the associated disability assessment instruments.

This chapter provides a summary and analysis of the key informant data, focus group data, and centre description information. The information gathered by the centres shows both strong commonalities and significant cross-cultural variation in societal responses to disabling conditions.

### Methods

The overall CAR study focused on 12 basic data needs. Eight of those needs are discussed in this chapter, and the remaining four needs are presented in Chapter 20. The needs addressed here are:

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1. To create a general description of the place and meaning of disability and disability programmes in local cultures;
2. To summarize informants' descriptions of the current programmes, and need for programmes, that serve populations with disabilities;
3. To explore cultural contexts, practices, and values concerning disability;
4. To establish information on the thresholds that determine when, culturally, 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 disabilities associated with mental health, alcohol and drug problems, and physical conditions;
7. To investigate information on stigma attached to various types of disabilities; and
8. To explore alternative conceptual models for the classification.

Table 1. Matching methods with relevant data needs

Research methods (Types of data collected)	Research issues for project	Data needs
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	General description of the meaning of disability; description of the current programmes; cultural contexts, practices and values concerning disability; parity or lack of parity; exploring alternative models; identifying linguistic equivalences for conceptual transfer
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	Cultural contexts, practices and values concerning disabilities; thresholds of disabilities; relative importance of different types of disabling conditions in different cultures; parity or lack of parity; 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	

As was described in Chapter 2, each of these needs was carefully matched with one or more of the CAR methods. One of the goals of this matching was to assure that multiple methods were used to approach each data need, and that each need was covered by at least two, and preferably more, methods. This methods-matching approach turned out to be very valuable in the overall conduct and analysis of the project goals and data sets. Table 1 presents the matches between the methods and data collection needs reported in this Chapter. Pile sorting and concept mapping results are described in Chapter 20.

The CAR research was conducted at 20<sup>1</sup> sites in a total of 16 countries. Table 2 describes the number of informants represented in the data collected by all sites for these methods.

Table 2. Numbers of informants or data collection and reporting sessions

Method	Total N (all centres)
Centre	15
Key informant <sup>2</sup> interviews	230 informants at 18 centres
Focus groups	22 focus groups at 7 centres

## Results related to global issues

The global issues examined in the CAR study, such as stigma, thresholds and the general meaning of disability in the local culture, are the key qualitative conditions explored across the centres and the data sets. Many of these issues had a shared cross-cultural and cross-national core on which the differ-

<sup>1</sup> The centres which completed all six data collection tasks included three sites in India (Bangalore, Chennai and Delhi), Japan, The Netherlands, Nigeria, Romania, and Tunisia. Tunisia was responsible for data collection in Egypt, so there was no separate centre narrative for Egypt. The centres which collected all of the data except the focus group data included Canada, China, Greece, Luxembourg, Spain, Turkey (with sites in Ankara, Istanbul, and Antalya), and the United Kingdom. The United States site (Flagstaff) did not collect key informant interview data or concept mapping data. The Cambodian site was a later addition to the field group and provided a centre description, key informant interviews, focus groups data and the revised item evaluation data set. The sites that collected focus group data included Cambodia, India (three sites), Japan, The Netherlands, Nigeria, Romania, Tunisia, and the United States (Flagstaff).

<sup>2</sup> "Key informants" were defined as those who, by virtue of their position and knowledge, can capture and reveal relevant cultural phenomena, especially on disability. Within each site, 15 informants were to be selected, composed of three individuals representing the following five groups: health professionals (e.g., physicians, psychiatrists, psychologists, nurses), allied health professionals (e.g., social workers, case workers), policy makers or opinion leaders in the area of disability services, persons with a physical health condition (or their care-givers), and persons with a health condition in the area of alcohol, drugs or mental health (or their care-givers).

ent groups agreed. However, there were also strong differences in the emphasis, the valuation, and the local reaction to disabilities that emerged in the cross-cultural data sets.

### *Perceptions of current practices and programmes*

Some of the most powerful data on the availability of programmes to assist disabled persons were collected during the focus group sessions held at each site. Participants discussed the programmes that were available, those that were not available and should be, and the reasons why they felt the coverage and the gaps existed. As noted in Chapter 3, there were three possible focus group topics and question models. For this issue, the data from the current practices and needs focus groups were found to parallel and augment the data from the parity and stigma focus groups in many ways. Part of the data from both data sets is compared and contrasted below to answer both sets of questions that were asked.

The amount of information focus group participants had about the law and the availability of services varied widely from individual to individual and group to group, depending on their exposure to the law and the assistance systems. Health professionals often had limited knowledge of the overall social programme systems in their society. Individuals with disabilities, and their caregivers, knew the most about programmes, services, laws, and conditions, especially those directly related to the disabilities that affected them. They tended to be more knowledgeable in those areas than many of the health professionals, with the exception of persons who worked for specific disabilities services. Health professionals have extensive knowledge of the disabilities that concern their area of specialization, but have limited knowledge (and occasionally no knowledge) of the laws, social service programmes, or advocacy and self-help groups associated with various other disabilities.

The participants indicated that many of the laws and programmes on disabilities focus on categorical conditions. There are programmes for the blind, deaf, and physically immobile, and other special categories, such as individuals who have served in the armed forces. But there is frequently no comprehensive or integrative system that embraces all disabling conditions. As a result, in order to qualify for various social assistance or income support programmes, the disabled individual is assessed in terms of diagnostic categories, i.e., not in terms of the activities that he or she can actually perform, but in terms of the categorical impairments he or she has. These assessments can be incomplete, irrelevant, or sometimes harmful. People with disabilities confront what they believe are a range of conflicting and non-interacting programmes each with

different selection criteria and different types of help on offer. There is also a clear disparity in services provided depending on the stigma attached to different disabilities. Disabilities associated with mental health conditions and addictions are the most stigmatized and the least likely to receive adequate services or funding across all of the cultures reporting on the CAR study.

### *The cultural context of disability programmes*

Five scenarios describing different health conditions were presented to key informants, as the primary method to determine the social and cultural contexts associated with disabilities and disability programmes. After some other questions, discussed below, informants were asked whether people in their culture believed that someone with a serious problem of that sort should get social assistance from the State. Comparing their responses when the serious problem was associated with a physical, mental, or drug or alcohol disorder revealed the implicit social context underlying these judgements (see Table 3).<sup>3</sup>

A majority of informants in each culture answered "Yes, assistance should be provided" for a serious mobility problem and for activity limitations linked to a serious intelligence problem and a serious mental disorder. However, they had considerably more reservations about providing assistance for the intelligence and mental disorder than for the mobility problem; in most societies, a minority gave the answer "It depends on the cause of the problem and its severity." In over half of the societies, a majority said "No" to the provision of assistance for a serious alcohol problem, and in about half of the societies the preponderant response was also "No" also for a serious heroin problem. Behind the "No" responses was likely to be the perception that the alcohol or heroin problem was self-induced.

In a related fashion, many of the "Yes" responses added that the provision of social assistance should be conditioned on the person being in treatment and motivated to change. In the context of alcohol and drug problems, social support tended to be viewed as an incentive for the affected person acknowledging a "need for assistance" defined in terms of treatment. The formulation in terms of having a "need for help" in the case of alcohol or drug problems often points towards compulsory rather than voluntary treatment.

Table 3 provides evidence that there is a clear downward gradient in support for state income and other forms of social assistance in most soci-

<sup>3</sup> The example given of a physical health problem is "Having difficulty walking or getting around unaided." In most people's minds, and not without reason, a mobility problem is caused by a physical health condition. It should be noted, however, that as a disability, a mobility problem could also be associated with a mental health or drug- and alcohol-health condition.

eties from disabilities associated with a physical condition and those linked to mental impairments and alcohol and drug problems. Support is high for social assistance for physical disabilities, and at best limited for social assistance for alcohol and drug problems. Once again, in the latter case the support for assistance was often conditioned on the person seeking treatment.

The key informant summaries indicate that popular attitudes are not supportive of parity in social assistance between physical, mental and alcohol and drug disorders. Even in societies where a majority of informants reported that there is support for social assistance across the board (China and Japan), there were substantial minority views concerning the alcohol and heroin disorders, as well as a suggestion that official views often run counter to actual practice in many different societies.

The data suggest that a number of presumptions lie behind societal views on social assistance. The most important of these involves the issue of where responsibility for the condition lies. Uncontrollable drinking and heroin use are widely seen as self-induced, and cross-culturally there is less sympathy for social assistance where the disabling condition is thought to be self-induced. On the other hand, when the etiology of a condition (whether physical, mental, or relating to substance use) is unequivocally assigned to causes outside the individual's control, there is generally more sympathy for the person with the condition, and more cultural support for the provision of assistance at a societal level. In many societies, conditions ascribed to fate, luck, or genetics are viewed sympathetically, although even here the sympathy does not apply if the person is seen as having contributed to the bad luck by his or her own actions.

There is also a clear exception to this general finding of greater sympathy for conditions with causes external to the individual. People in cultures that maintain a strong belief that bad outcomes reflect bad behaviour somewhere in the past, whether by the affected person or by the person's family, are far less sympathetic to people whose disabilities have been present from birth. Nigeria provides the clearest example of this: a majority of informants said that a mobility problem or a mental disorder present from birth is viewed as a divine sign that the parents did something bad. Key informants noted this theme also in India, and stigma for the family from a presumed genetic defect was implied in Greece, Japan and Turkey.

The degree of stigma or social disapproval attached to a condition seems to be strongly related to a reluctance to support state social assistance. It might be expected that individuals who confront the greatest barriers to participation in society would be thought to be in the greatest need of social assistance. But our informants report otherwise: there is a reverse correlation between orderings on the impact dimensions of various disabilities and the

Table 3. Support for social assistance for five conditions

Scenarios:  
 (a) Some people have difficulty walking or getting around unaided as the result of a health condition.  
 (b) Some people have difficulty with the activities of everyday life because they were born with low intelligence.  
 (c) Some people have difficulty with the activities of everyday life because they are bothered by strange thoughts, and sometimes they cannot control their actions.  
 (d) 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.  
 (e) Some people have difficulty with the activities of everyday life because they take heroin. They are unable to control the amount of heroin they take or how often they take it.

Country	(a) can't walk	(b) low intelligence	(c) strange thoughts	(d) uncontrollable drinking	(e) uncontrollable heroin use
Canada	Yes	Yes (depends on severity and whether family/friends can support)	Yes (depends on degree or seriousness of problem)	It depends on severity and if in treatment (no. because it was own choice to drink)	Yes, but the person must be in treatment (no. because self-inflicted. depends on severity of problem)
China	Yes (depending on degree)	Yes (depends on severity)	Yes (sympathy, because of harm to self and society)	Yes (6 said no)	Yes (6 said no)
Greece	Yes	Yes (but some people do not care)	Yes, if a serious problem, (it depends, less popular support for mentally ill than for physically ill)	No (it depends, treatment but no financial help. 5 said yes)	Yes (no, it depends, treatment but no benefits)

Would people around here think they should get [state social assistance] if the problem was serious? – Yes; No; It depends.

India	Yes (depends on the individual & need, whether because of war or military service, depends on financial need)	Yes (depends on economic status, independent of economic status, no)	Yes (depending on seriousness, no, depending on financial status)	No (but treatment help, assistance to family, yes "people see this problem differently and are moralistically judgemental about it")	No (only treatment help, yes family members need assistance, "de-addiction" assistance should be given)
Japan	14 said yes should get assistance (2 said depends on the case)	Yes (1 said "it depends")	All said yes should get assistance	(7 said yes; 5 said no; 4 said depends on severity of case)	Yes (1 said no; 1 said it depends; 2 non-responses)
Luxembourg	11 said yes (3 said it depends if the person shows goodwill, 2 said it depends - not if due to alcohol/drugs)	12 said yes: (1 no; 3 it depends on degree of dependence/family support)	7 said yes (1 no; others: it depends on people's knowledge about these diseases, on degree of dependence, if person considered "crazy")	9 said no (2 yes; 4 it depends, including whether seen as disease)	8 no (3 yes; 4 it depends)
The Netherlands	Yes	Yes (1 said no)	Yes (no more difficult for mental than physical cases, partly because of inconvenience/nuisance for those around)	No (when it's related to life events, when the person seeks treatment. 2 said yes)	No (yes, yes with conditions)
Nigeria	8 said yes	7 said yes (no, it depends: more assistance in better educated/higher status communities)	Yes (8/15 no, it depends on whether seeking help/self-induced)	No (yes, it depends if looking for help, on severity of problem)	8 said yes (7 said no)
Romania	13 said yes (2: it depends on the degree of impairment)	Yes (1 said it depends on severity)	Yes (14/15 said it depends on severity & treatment access)	No (yes, it depends on somatic complications)	No (4 said yes)
Spain	Yes	Yes (2 said yes if unable to work)	Yes (if not able to work)	[both professionals and patients split on "yes" or "no because self-induced"]	[both professionals and patients split between "yes" and "no because self induced"]
Tunisia	Yes	Yes	Yes	No	Yes (majority; if stops/isolated, no)
Turkey	Yes	Yes (if serious)	Yes (majority; it depends on tolerance in family/on diagnosis)	No	No (majority; if motivated and severe, yes)
United Kingdom	13 said yes (it depends on whether wanted)	Yes, (1 said it depends on ability to work or receive family support)	Yes (9/15; 5 said it depends on response to treatment)	7 said no (6 said it depends on attitude to treatment, 2 said yes)	[missing data]

reported enthusiasm for state social assistance. There is strong support across the board for social assistance for a person with a mobility problem. In most societies social participation was more expected and less constrained for this condition than for any of the other four conditions.

*The influence of etiology on judgements about disabilities*

As a follow-up to the questions on social assistance, the key informants were asked whether the etiology of the problem would affect "how others thought of the problem and how the person was regarded." For the scenario on walking difficulty and "strange thoughts," respondents were then asked if it would make a difference to peoples' attitudes if the condition had been present from birth, and if it had resulted from a road accident. Table 4 summarizes the responses across centres.

In most societies it was felt that both of these etiologies would produce more understanding and sympathy than otherwise. However, in Nigeria it was felt that the presence of a problem from birth would further stigmatize the person, rather than lessen stigmatization; it would be felt that the affliction must be a curse from God. A minority of informants in Greece, India and Japan also mentioned that the affliction would cast aspersions on the parents or the person's genetic heritage (family prestige). And some informants in the United Kingdom felt that in this circumstance it would be assumed that there must also be a mental disorder associated with the other conditions. So, while the overall result was that these conditions were not strongly stigmatized, interpretations in some cultures could cause them to be stigmatized.

There were some other variations from the general tendency of responses concerning the impact of etiology on a mobility problem (first two columns of Table 4). A majority of informants in China felt that the fact that the mobility problem resulted from a road accident would not bring more sympathy. In India, a minority felt that the blame would actually be increased in this case with the occurrence of the accident being seen as a reflection of the person's past sins. In several societies (Canada, Japan, Luxembourg, The Netherlands, Romania, United Kingdom) a minority of the key informants mentioned that there would be more sympathy only if the circumstances of the accident made the person an innocent victim; in Canada and the United Kingdom, informants specifically mentioned that there would be no sympathy if the accident was seen as caused by the person's drinking or drug use. A few informants in Canada and the United Kingdom also mentioned that attitudes to the accident victim would be influenced by perceptions of who caused the accident.

**Table 4. Influence of etiology on how problem was viewed: mobility problem v. mental disorder**

What if the problem was something the person had had from birth – would that affect how others thought of the problem and how the person was regarded? In what ways?		What 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?	
Scenario:	(a) can't walk	(c) strange thoughts	(c) strange thoughts
Etiology:	If from birth	If from birth	If from road accident
Canada	Great pity and sympathy	Less blame, would not affect regard, would be lower expectations	Would not affect regard, pity and sympathy for their loss, depends on cause of accident
China	8 yes affected – more sympathy & help (7 no, would not affect)	10 said no effect (5 said yes, it would affect – more despised, more stigma)	8 said no effect (6 said yes, it would affect positively, in terms of compensation, public opinion, sympathy, I said yes, stigma)
Greece	Negative effect from stigma for family, would not affect attitudes, would increase sympathy	Negative effect since regarded as responsible for problem, increase sympathy, no effect	Would increase toleration; would make no difference
India	More sympathy and understanding (no difference, considered a burden/sign of parents misdeed, sign of fate or supernatural punishment)	More sympathy and understanding (no difference, blamed more because of the accident, pity but also blame, fate, problem due to person's past sins)	Sympathy and pity (more acceptance, less sympathy – considered worthless, will not change attitudes, considered as fate)

Japan	More sympathy (our society should help, genetic problem, bad luck)	More sympathy, no difference (bad luck, depends if victim or cause)	More sympathy, genetic problem, would not happen (avoid family)	Sympathy because it could happen to anyone, rarely happens (depends on the accident)
Luxembourg	More comprehension (no difference, risk of transmitting to children, more pity, feel helplessness, problem is more important)	Yes (depends if person's fault, no)	No difference (easily accepted, definitely classified, pity, person used to it, can happen to anybody)	Yes more easily accepted (pity, depends if person is responsible, no difference)
The Netherlands	Yes, positively; more compassion/understanding/acceptance (no)	Yes, positively (more compassion/pity where cause is outside the person, no, it depends)	Yes, more sympathy (no)	Yes, attribution to external cause brings more tolerance and compassion (no)
Nigeria	Worse if from birth – he is a sinner, the parents did something, it is a curse from God (more sympathy)	More sympathy – the family is not stigmatized because it could happen to anybody (it depends-could be seen as retribution for misdeeds, no difference)	Worse attitude (8/15 – “sent from the devil,” act of God; greater sympathy, no influence)	More sympathy – could happen to anybody and “not as a result of someone’s own faults.”
Romania	10 more tolerance (3 worse, a real handicap)	9 more tolerance (4: the same; 2: it depends on the circumstances of the accident)	Worse attitude (9/15; more indulgent, no change in attitudes)	More indulgent – 7/15; no change in attitudes – 7/15; worse attitude
Spain	{Sample split on whether more compassion, less, or no difference if problem is from birth}	{Sample split on effect; detailed information missing}	More indulgent attitudes if from birth (no change)	{Missing data}
Tunisia	Acceptance (it's a matter of destiny), try to adapt (pity)	Feel solidarity, accept the situation (poor acceptance of the situation)	Getting used to the situation, it's one's destiny, support of family	Feeling of solidarity (mistrusting the person)
Turkey	No effect – 6/15; more sympathy – 5/15; less sympathy – 4/15	Some say will affect feelings, some not; most agree the situation is the person's fate	More sympathy and mercy (most; more anxious because will think hereditary)	More sympathy/fate/mercy/help (14/15; no effect)
United Kingdom	No effect – 4/15; protectionism/patronizing/sympathetic – 5/15; stigmatizing – 3/15; “If physically disabled, it is assumed must have mental disability” 7/15	More sympathetic if innocent victim – 7/15; no sympathy if caused accident through drugs or alcohol – 6/15; stigmatize – 3/15; no effect – 1/15	Split responses; 3/15 sympathetically, 5/15 less sympathy/exclusion/wary	More sympathy if innocent party – 7/15; less sympathy if from drink or drugs – 3/15

The key informant responses were very mixed in their interpretations of the influence of birth or an accident as the etiology of a serious mental disorder (Table 4, third and fourth columns). For a mental problem seen as being present from birth (which a couple of clinicians pointed out was unlikely for the mental problem as described), the balance of informants' views in Nigeria and Romania tipped toward thinking that it would produce a more negative attitude. Informants' responses on this were split in Canada, Greece, Luxembourg and the United Kingdom. In China, a majority said that this etiology would make no difference. Only in India, Japan, The Netherlands, Spain and Turkey did clear majorities say that more sympathy would be given to individuals who had this type of condition from birth, or after an accident.

On the other hand, where the problem resulted from a road accident, there was a clear majority that there would be more sympathy in Greece, India, Japan, The Netherlands, Nigeria, Tunisia and Turkey. In Canada, Luxembourg and the United Kingdom, opinions on this were split, as they were in relation to sympathy towards a problem that was present from birth. Again, the proviso that it depended whether the person was seen as responsible for the accident was mentioned in Canada, Japan, Luxembourg and the United Kingdom. Informants in The Netherlands and Nigeria specifically mentioned that being able to attribute a condition to an external cause brings more sympathy because the problem is then seen as one that could happen to anyone and is not "a result of someone's own fault."

This theme of personal responsibility became vividly apparent in responses to the scenario on an alcohol and a heroin problem. Informants were asked what difference it would make if the behaviour was seen as resulting from a death in the family (Table 5). We had hypothesized that such an etiology might be seen as potentially exculpatory for the condition in cultural situations where it was otherwise stigmatized.

The key informants' responses demonstrated that the stigma responses were sometimes modified or reduced in intensity from general disapproval, but there is a very clear message that compassionate or tolerant attitudes were conditional on whether the person voluntarily sought help or accepted involuntary help. The impression is also given that sympathy might not be long lasting. If a serious alcohol or heroin problem was seen as resulting from a death in the family it would generally produce more sympathy and tolerance, but not in Tunisia for either alcohol and heroin, nor in Canada, China, Luxembourg and The Netherlands for heroin.

The findings of this analysis underscore the fact that the terrain of disability, touching as it does on the whole gamut of daily life, is heavily influenced by social attitudes, including moral views. Beneath the varying degrees of

*Table 5. Influence of etiology on how problem was thought of: alcohol and heroin problems*

What if the problem was seen as 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?

Country	(d) Uncontrollable drinking	(e) Uncontrollable heroin use
Canada	More sympathy and tolerance, but only for a certain period afterwards	No effect on how others thought, "no excuse" for using heroin (some sympathy, but only for short period)
China	8 said yes would affect – more sympathy (7 said no would not affect)	10 said no would not affect (5 said yes – more sympathy)
Greece	More positive attitude in this case, but only for a short period (would not really make a difference)	More positive attitude (but only for a while, makes no difference, less tolerance than for alcohol)
India	More sympathetic, but only as a temporary problem (no change, just an excuse, it's a bad habit)	More sympathy, but only for the short term (no difference, not if engages in antisocial acts)
Japan	[Missing data]	[Missing data]
Luxembourg	Tolerance and compassion for only a short time (no difference, more pity)	Makes no difference (3 said more tolerance, 2 said "yes, I said "depends on the drug")
The Netherlands	More understanding pity (but with a time limit, no effect)	No effect on other's view (should not react by taking drugs, yes on a temporary basis or because of external cause)
Nigeria	Greater sympathy (9/15; no sympathy)	Greater sympathy (9/15; no effect)
Romania	More compassion (13/15; no effect)	More compassion (12/15; no effect)
Spain	[Responses split]	! "Better tolerated for alcohol than for drugs"!
Tunisia	A negative view no matter what the reason (pity)	Negative reaction whatever the reason (acceptance at first, then not)
Turkey	Greater mercy and tolerance (most)	More mercy and tolerance (majority)
United Kingdom	Yes (more sympathetic 4/15, yes for a short period; 5/15; no 2/15)	[Missing data]



stigmatization of different disabilities found in all the societies studied, there are undoubtedly culturally informed prejudices. There are also judgements about the moral status of the disabled person that reflect deeply felt views of how lives should be lived and how the social order should be constructed. Though a classification of disability must be etiologically neutral, in the sense of not presuming causal connections between health conditions, impairments, activity limitations and participation restrictions, it is clear that attitudes about etiology and presumed causal history determine many of the societal attitudes towards disability, and consequently towards any programme of assistance that will be developed to reduce the global impact of disability. These responses must be factored into the equations for understanding disabilities across and within cultural systems.

### *Cross-cultural variation in perceived thresholds of disabling conditions*

Almost universally, the CAR centre reports indicated that having a systematic way of establishing the level, or threshold, at which disabling conditions should receive societal assistance was a common need. The reports also indicate that there is cultural variation about where these thresholds should be drawn.

An earlier cross-cultural applicability study of alcohol and drug disorders (Room, Janca, Bennett et al. 1996; Schmidt & Room 1999) demonstrated that there was considerable variation between cultures in the thresholds at which behaviours or conditions are noticed at all or are defined as problematic. These variations potentially affect cross-cultural epidemiological comparisons and have wider implications for health status and service utilization.

To make matters more complicated, thresholds can exist at various levels. There is the threshold of a condition being noticed. There is also the threshold where a condition is identified as a disability. In everyday social behaviour, occasional awkwardness, slowness or difficulty in behaviour or demeanour may not be noticed at all, or may not be called a disability. Whether and how stiffness in walking, breaking off and restarting sentences, or a minor facial tic is noticed is subject to variation both between and within cultures. Then, there may be additional substantial variation between cultures in terms of the levels at which a condition is viewed as a matter of some seriousness. Perceptions of seriousness may reflect aspects of the physical and social environment, as well as the level of individual impairment. What might otherwise be a serious problem may become much less serious when functional aids or environmental modifications are routinely available, or when eccentricity or other minor variations in personal style are readily accepted in a particular culture.

The key informant interviews explored the issue of thresholds by means of five anchor scenarios<sup>4</sup>. In each scenario, a health-related condition was said to cause difficulties with the activities of everyday life. The five scenarios were described as follows:

1. *Mobility problem*: "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."
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."
3. *Low intelligence*: "Some people have difficulty with the activities of everyday life because they were born with low intelligence. Sometimes their difficulty with this is obvious, but sometimes it is not."
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."
5. *Heroin problem*: "Some people have difficulty with the activities of everyday life because they take heroin. They seem unable to control the amount of heroin they take or how often they take it. Sometimes the difficulty with this is obvious, but sometimes it is not."

For each scenario, the respondents were asked three questions about thresholds:

- a) If someone had a problem like this, but it was quite mild, what aspects of the person's behaviour might first attract the attention or notice of others, such as family members, neighbours 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)?

<sup>4</sup> The questions on thresholds were included in the key informant substudy of the CAR study. The present data analysis includes data from 11 countries. At the other sites, either insufficient data were collected, or they were summarized into English in insufficient detail for the present analysis. Each participating centre was asked to interview 15 key informants with an instrument combining questions with closed-ended codes and open-ended questions. For information about how key informants were selected see note 2. In India, three sites participated in the study. The actual number of key informants interviewed in each country is as follows: Canada 15, China 15, Greece 15, India 47, Luxembourg 16, The Netherlands 13, Nigeria 15, Romania 15, Tunisia (including Egypt) 15, Turkey 15, and the United Kingdom 15.

- c) What would people consider to be signs that this person needed help from someone else with the activities of everyday life?

The wording of the first question was intended to introduce a minimum threshold, implicitly below the levels tapped by the other two questions. No assumption was built into the wording of the questions concerning the relative levels of severity of the second and third questions, although the fact that the question about needing "help from someone else" was placed third might have been assumed to imply greater severity. "Needing help" with a disability obviously implies an investment of human resources, whether paid or unpaid. In cultures placing a high value on individual autonomy, it may also be a dividing line infused with social meaning.

The responses to the questions about the mobility problem scenario most often started from the cue built into the question ("difficulty in walking or getting around"). There was fair agreement across the cultures that the threshold of attracting attention or notice includes such visible signs as slowness, stiffness, or limping. Unsteady balance was also mentioned at four sites (Canada, China, India, and The Netherlands). Informants in most countries focused on these physical signs, but some key informants mentioned that their culture also recognized psychological signs (nervousness and irritability - Greece, acting childishly - The Netherlands; avoidance of moving - Romania and United Kingdom; and looking for help - The Netherlands and Nigeria) that were associated with this threshold level.

The threshold between notice and seriousness was often demarcated by the use of an assistive device such as a stick, wheelchair, or other technical assistance. Differences in the availability of technical aids in some areas also produced mentions of "moving on all fours" or that the affected person "has to crawl." Falling or an injury were mentioned in five societies (Canada, India, Luxembourg, The Netherlands and Romania). While in China psychological sequelae (changes in consciousness, committing suicide) were mentioned in this context, in several societies (Canada, Greece, India, Nigeria, Romania, Tunisia, and United Kingdom) limitations in self-care activities were mentioned as criteria for establishing this threshold level.

The threshold for needing help was primarily answered by the respondents first assuming that help was needed and then listing the types of help that would be provided. This response made the identification of the threshold more difficult, and less clear. At five sites (Canada, Greece, The Netherlands, Romania, United Kingdom), respondents mentioned that the fact that a person asked for help was a sign that the person needed help. Answers from China and Nigeria implied a higher degree of disability for needing help than for a serious problem, mentioning paralysis or being unable to change posi-

tions. Most answers kept to a description of physical limitations that were associated with this threshold level. There were just a few mentions of psychological factors that could be associated with this threshold level (frustration, anger, or depression - United Kingdom; danger - Romania).

The mental disorder threshold for attracting attention or notice was defined by the presence of "out-of-context or inappropriate" social behaviours. These behaviours tended to relate to "irrational talk and behaviour," as a Nigerian respondent put it. Dangerousness (including aggression and hostile moods) was included by a number of informants from several countries: Greece, India, The Netherlands, Nigeria and Romania.

Several versions of "strange and odd behaviour" or talk were mentioned in most cultures as the salient criterion for identifying a serious problem. A notable criterion for establishing the threshold of a serious mental disorder almost everywhere (except The Netherlands) was aggression, violence, or harming others. In a majority of sites, poor self-care or being dirty or unkempt were also mentioned as criteria for identifying a serious problem.

The responses for the threshold of needing help were similar to, but more extensive than, those associated with the threshold of identifying a serious problem. The threat of aggression or harm to oneself was a prominent theme in a majority of cultures. Neglect of self-care was also mentioned in a majority of cultures, although informants in China and Tunisia focused more on impaired communication and comprehension. Asking for help was mentioned in fewer societies (India, The Netherlands, and the United Kingdom) than for the mobility problem. Overall, the thresholds for serious problems and individuals needing help were virtually identical for mental problems.

The low intelligence threshold scenario produced many responses that focused on childhood slowness or retardation. The threshold for noticing this condition was the most clearly dependent on age, and the comments about intervention tended to be age-specific as well. Difficulties in communication were mentioned as one sign of impairment by informants from many cultures, but the pattern of responses suggests that the threshold for this condition may be set at a more extreme level (only noticed when a person cannot communicate at all) in China than elsewhere. The focus of the threshold recognition conditions was on cognitive disabilities, but there were also some mentions of difficulties in social functioning (China - no sense of shame; India - silly behaviour; Romania - childish behaviour; Nigeria - unkempt, abnormal behaviour) as part of the recognition process.

Little differentiation is made between the threshold of notice and the signals of a serious problem for low intelligence in many cultures. The cognitive dimensions of functioning figured in most answers concerning a serious problem, but an added element of the responses from many sites was a di-

mension of dangerousness or social deviance added to the other conditions. Aggression or temper tantrums were mentioned in the responses from Canada, India and The Netherlands; other responses pointing in this direction were added by other sites: lacking a sense of danger (China); causing accidents or fires (Turkey); coarse or inappropriate demeanour (Tunisia); and indulging in vices (Nigeria).

At nearly all sites, the criteria for identifying the threshold of where when help is needed included problems in self-care or in performing basic activities. But in conjunction with this, a majority of informants in all societies mention a dimension of dangerousness to others or lack of a sense of danger to oneself (China, Greece, India, Romania), of aggression or anger (India, Tunisia, United Kingdom), or of a lack of judgement or moral reasoning (Nigeria, United Kingdom) as key threshold criteria.

For the alcohol problem scenario, informants offered a variety of signs that might first attract attention or notice to an alcohol problem. Many of these are related to specific drinking-related behaviours or signs (e.g., slurred speech, smell of alcohol). These threshold conditions often carried the implication that it is the repetition of the behaviour that counts, not just a single instance or instances that were very far apart ("a lot of drinking" - China; "excessive drinking habit" - India). A dimension of compulsiveness or pre-occupation with use was mentioned in several sites (Canada, China, Greece, and United Kingdom). In a majority of sites the threshold of notice included poor performance in work or family role responsibilities. The idea of erratic behaviour or a change in behaviour was mentioned at several sites.

This was the first scenario that produced a clear pattern in which socially derogatory signs were identified even at the level of first notice of the problem. These included aggressiveness (Greece, India, Nigeria, United Kingdom), irritability (Romania), lying (India, United Kingdom), and vagabondage (Tunisia).

Responses from Tunisia emphasized physical and psychological signs to indicate a serious alcohol problem, along with "refusing advice" and "loss of conscience." At all other sites, neglect of major social roles was the key response, along with aggression and violence. Only four societies (Canada, Greece, India, and United Kingdom) included responses from key informants that identified physical health problems as signs that the problem is serious.

The criteria for needing help did not seem to differ greatly from the criteria for a serious problem in this scenario. A person's failure in his or her social roles and acts of violence was prominent in the identification of the seriousness of the problem, along with a variety of physical, psychological and social signs. Tunisian informants emphasized "danger to others" as a criterion, and this theme also appears more diffusely elsewhere (e.g., in Greece

and India where there was mention of the family needing help). This response alerts us that "needing help" in some cultural contexts is socially defined in ways other than volunteering assistance to the person with disability. It can imply a societal demand for compulsory treatment for the individual as well as assistance to others who are affected by the person with the problem. In contrast to the first two scenarios, no site mentioned "requesting help" as a sign of needing help with a serious alcohol problem.

The primary emphasis in responses to the heroin problem scenario, on what would first attract attention or notice, was on behavioural and mood changes. Though some physiological signs were offered (e.g., "glassy eyes" - India; "scratching one's nose" - Tunisia), the main signs mentioned for a heroin problem were more generalized than for alcohol. Fewer sites mentioned aggressiveness or irritability, but lying (China, India) or secretive behaviour (Canada, Nigeria) were mentioned.

For the threshold signs for a serious level of impact, aggression was less commonly mentioned for heroin than for alcohol, although it was mentioned in Greece, India, Luxembourg, Nigeria and Romania. Involvement in criminal activities was often mentioned. Defaults in major social roles were somewhat less prominently mentioned than for alcohol. It is possible that there is less direct knowledge of the physical signs of heroin addiction among this set of informants, and therefore they had to rely on general social knowledge to be able to discuss the threshold scenario.

The criteria for needing help were, as with alcohol, not clearly distinguished from signs of a serious problem. At a majority of sites, lack of self-care or being dirty or untidy were mentioned; other recurrent themes were neglect of daily tasks and antisocial behaviours. "Danger for others" was explicitly mentioned only in Tunisia. As with the alcohol scenario, there was no mention of "requesting help" as a sign of needing help.

When the responses to all of the scenarios are compared, it is interesting that the key informants often did not give information that created very clear differentiation between the three thresholds of attention, serious problem, and needing help. This was especially true for distinctions between the thresholds for "serious problem" and "needing help": the answers to the two were either identical or only minimally distinguishable. With the exception of the scenario on mobility, dangerousness to self or others was often an element used to differentiate the threshold of notice and that of a serious problem. In responses to the need for help threshold, the added element was often failure in self-management of mundane activities. For the mobility scenario, and less commonly also for the mental disorder scenario, asking for help was mentioned as a sign of needing help.

Responses to both the alcohol problem and the heroin problem scenario

usually emphasized morally defined signs, even at the minimum threshold of being noticed. The individual's failure to perform social roles, and aggression or violence, were commonly cited as signs of alcohol problems; with heroin, the emphasis was less on violence and more on secretiveness. For those with alcohol and drug problems, there is the added burden of the tendency to see the problem as voluntarily assumed; as one respondent from the Netherlands put it concerning indications for needing help for the heroin problem scenario, "no help because no sympathy." In contrast, while a person with a mental disorder or low intelligence may also fail to fill major social roles, this failure is not described as part of the problem, but as a consequence of the problem. At the far end of this spectrum, responses concerning restriction of mobility were not oriented to inherently negative social evaluations.

The responses of the CAR key informants suggest that the five problems asked about are widely defined in terms of a moral gradient, in which a physical mobility problem is the least negatively evaluated in social terms, and alcohol and drug problems are most negatively socially evaluated. The key informant responses for the mental disorder and low intelligence scenarios were generally less negatively socially assessed than responses for alcohol and drug problems. Only the physical mobility problem responses rarely contained a moralized dimension in all cultures. The intensity or steepness of the moral gradient varied across cultures. The differential across the five scenarios seems somewhat less in Canada, for instance, than in India, but the existence and direction of the gradient is clearly evident in responses from every society.

#### *The relative importance of disabling conditions: The ranking exercise*

A substudy within the CAR key informant study addressed the question of how different cultures rank or rate the seriousness of different disabling conditions (this study is reported in Ustin, Rehm, Chatterji et al. 1999). From the perspective of the CAR research, it was important to discover whether there were any meaningful differences in the ranking of the disabling effects of health conditions by key informant from different countries. It was also of interest to discover whether different informant groups (medical professionals, allied health professionals, health policy-makers, consumers or caregivers) rank health conditions in meaningfully different ways.

Key informants from the participating countries were presented with a deck of 17 cards listing different health conditions (see Chapter 3 for details). They were asked to rank the conditions from the most to the least

disabling. The "most disabling condition" was described as that which would make daily activities very difficult; the "least disabling" was described as that which would not interfere with the activities of everyday life. Numerical codes were assigned to the 17 conditions, with "01" representing the most disabling, and "17" representing the least disabling.

Non-parametric statistics for ordinal-level variables were used to analyse the data. Overall ranking was established on the basis of the median. Health conditions with the same median were ranked using the arithmetical mean as the second criterion. To test for differences between countries or informant groups, Kruskal-Wallis rank order analysis of variance for one factor was used. Spearman and Kendall Tau B correlation coefficients were computed to measure the association between different rank orders.

Table 6 gives an overview of the relative rank order for the 17 health conditions, ranked from most disabling to least disabling. Overall, quadriplegia was considered the most disabling condition across all cultures, followed by dementia (rank 2), active psychosis (rank 3), and paraplegia (rank 4). At the opposite end of the spectrum, having vitiligo on the face (least disabling = rank 17), being infertile when a child is desired (rank 16), and having severe migraines (rank 15) were deemed the least disabling. The conditions at both ends of the spectrum, that is the most disabling and the least disabling conditions, showed lower variability than the conditions in between (see standard deviations in Table 6).

There were deviations from this combined measure of order within countries. Table 7 shows that in The Netherlands and Canada, for instance, active psychosis is seen as more disabling compared to the overall-sample rank, whereas in Tunisia it is seen as far less disabling. Being HIV-positive is considered relatively less disabling in Japan, Luxembourg, Spain, Turkey and the United Kingdom, whereas it is considered the most disabling in Egypt and Tunisia. HIV-positivity is, in general, the health condition with the most variation in rank (see also Table 6).

Statistically, the differences between countries were significant for } 3 out of 17 health conditions on the Kruskal-Wallis test. Only quadriplegia, paraplegia, below-the-knee amputation and mild mental retardation did not show rank differences between countries at the 0.05 significance level. It is interesting to note that three out of the four conditions that are judged uniformly across countries are prototypical physical disabilities. The fourth, mild mental retardation, does not show the same degree of uniformity as the other three.

Although there are statistically significant differences of ranking between countries, the convergence of judgements is also quite evident. The Kendall Tau rank-order correlations between different countries averaged 0.615 and the Spearman rank correlations averaged 0.777, which can be considered

relatively high given the variation among the cultures and experts participating. Within this average, there are clear cultural differences for some comparisons; for example Japan and Tunisia have a Kendall rank order correlation of 0.441 (Spearman: 0.581), or The Netherlands and Tunisia correlate at 0.294 (Spearman: 0.431). This would suggest that there are clusters of cultural viewpoints about disability rankings, and some cross-cultural agreement, but there is no universal vision of the ranks across all disabilities.

The rank-order ratings of different informant groups are summarized in Table 8. Only four out of 17 health conditions had significantly different rank orders between different informant groups: HIV positivity, total deafness, mild mental retardation, amputation below the knee. Interestingly, again physical disorders are the most prominent, but in this case as conditions with the most significant differences. HIV infection is the most variable condition in this study. It was ranked from the most disabling of all health conditions in Egypt and Tunisia to the third least disabling condition in Luxembourg. The differences among expert groups are less dramatic but still important. The differential availability of expensive treatment may contribute to these quite different judgements. In general, it can also be said that the physical condi-

Table 6 Rank order of disabling effect of health conditions by severity

Health condition	Rank	Median	Mean	Standard deviation	N
Quadriplegia	1	2	3.349	3.184	241
Dementia	2	4	4.896	3.648	241
Active psychosis	3	4	5.290	3.626	241
Paraplegia	4	5	5.938	3.262	241
Blindness	5	6	6.780	4.037	241
Major depression	6	6	7.224	3.821	241
Drug dependence	7	8	7.847	3.874	222
HIV positive	8	9	8.791	5.155	239
Alcoholism	9	9	9.237	3.553	241
Total deafness	10	10	9.411	3.705	241
Mild mental retardation	11	10	9.851	3.555	241
Incontinence	12	10	10.159	4.087	239
Below the knee amputation	13	11	10.249	3.736	241
Rheumatoid arthritis	14	12	11.531	3.629	241
Severe migraines	15	12	11.629	3.789	240
Infertility	16	16	14.630	3.569	238
Vitiligo on face	17	16	15.000	2.410	238

Table 7 Disability ranks associated to different health conditions by country

Health condition (in rank order of total sample)	Country																
	Canada	China	India	Japan	Luxembourg	The Netherlands	Nigeria	Romania	Spain	Tunisia	Turkey	United Kingdom					
Quadriplegia (1)*	2	1	1	2	1	3	1	1	1	2	1	2					
Dementia (2)	3	8	2	1	2	2	6	2	2	3	2	1					
Active psychosis (3)	1	5	5	3	3	1	3	3	4	6	4	4					
Paraplegia (4)*	4	4	4	5	7	7	2	4	5	4	3	5					
Total blindness (5)	8	3	3	4	4	9	5	5	6	5	5	8					
Major depression (6)	5	6	6	8	6	4	4	7	3	7	11	3					
Drug dependence (7)	7	2	11	7	5	6	10	11	8	11	7	M					
HIV positive (8)	10	9	7	13	15	12	8	8	13	1	14	14					
Alcoholism (9)	9	10	10	10	8	5	13	13	7	12	10	6					
Total deafness (10)	11	12	9	6	9	11	15	9	9	13	12	12					
Mild mental retardation (11)*	6	11	12	15	10	13	11	10	10	9	8	7					
Incontinence (12)	15	13	8	14	13	15	7	6	12	10	6	11					
Below-the-knee amputation (13)*	12	7	14	9	11	14	12	12	11	8	9	13					
Rheumatoid arthritis (14)	14	14	13	11	14	10	14	15	15	16	13	10					
Severe migraines (15)	13	15	15	12	12	8	9	14	14	17	15	9					
Infertility (16)	16	17	17	16	17	16	16	16	17	15	17	16					
Vitiligo on face (17)	17	16	16	17	16	17	17	17	16	14	16	15					
N	15	15	43	18	16	13	15	15	18	15	15	12					

Note: Ranking ranges from 1 (most disabling) to 17 (least disabling). "Most disabling condition" defined as that which would make carrying out the activities of daily life very difficult, and the "least disabling condition" defined as that which would not interfere with activities of everyday life. Missing data, item not given.

\* No significant differences between countries on (P = 0.05 level)

Table 8. Disability ranks of different health conditions by informant group

Health condition (in rank order of total sample)	Medical professionals					Total (N=74)	Allied health pro- fessionals (N=51)	Health policy makers (N=35)	Consumers/ care-givers	
	Physical (N=14)	ADM (N=35)	Physical and ADM (N=14)	Other (N=11)	Physical (N=36)				Mental (N=45)	
Quadriplegia	1	1	3	1	1	1	1	1	1	1
Dementia	2	2	1	2	2	2	3	2	4	2
Active psychosis	5	3	2	4	3	3	2	3	2	3
Paraplegia	3	4	4	3	4	4	5	4	6	4
Blindness	6	5	5	5	5	5	6	7	5	5
Major depression	4	6	6	6	6	6	4	5	8	6
Drug dependence	9	7	7	8	7	7	7	9	7	8
HIV positivity	10	11	15	11	11	11	12	6	3	7
Alcoholism	13	10	10	9	9	9	8	10	9	9
Total deafness	12	8	9	7	8	8	10	11	11	12
Mild mental retardation	14	13	8	12	13	13	9	8	10	13
Incontinence	7	12	14	13	12	12	11	12	12	11
Below-the-knee amputation	8	9	12	10	10	10	13	13	13	10
Rheumatoid Arthritis	11	14	11	15	14	14	14	14	15	14
Severe migraines	15	15	13	14	15	15	15	15	14	15
Infertility	16	16	17	16	16	16	16	17	17	16
Vinigo on face	17	17	16	17	17	17	17	16	16	17

tions are ranked more uniformly and universally than mental conditions across countries, but not across informant groups.

#### Parity or lack of parity among health conditions

WHO has an international mandate to seek to create parity among health conditions. Parity is the goal of ensuring that society's health and related resources are provided to people according to their health requirements, not solely in terms of whether the underlying health condition can be characterized as a "physical" rather than a "mental" or "alcohol or drug abuse" health problem. In many of the countries involved in the CAR study, parity has not yet been achieved. Health insurance policies differentiate between whether the acquired condition is physical, mental or related to substance abuse; social benefits are allocated differently according to etiology and category of health condition. Even anti-discrimination provisions, in those countries that have them, often only apply to people whose disability is not the result of an alcohol or drug disorder.

The data from the CAR focus groups clearly indicate that in all the cultures sampled there is a stark lack of parity (both in the assistance provided and in attitudes towards individuals with disabilities) between physical, mental and alcohol- and drug-related disorders. Groups of health professionals, persons with disabilities and their families all unanimously agreed that a wide variety of negative social attitudes are common towards individuals labelled as mentally ill, or those with alcohol or drug problems. These are not as commonly directed towards persons with purely physical health conditions. Those who readily expressed their culture's compassion, understanding and willingness to accommodate people with physical health conditions often went on to note the culture's impatience, disdain, or even outright hostility towards alcoholics and mentally ill people. The most often cited basis for this difference was the extent to which the health condition is a result of voluntary actions or morally culpable behaviours. In the case of mental illnesses, most participants in the focus groups reported the cultural view that such individuals are unpredictable and probably dangerous.

A question on parity posed to the focus groups was whether, in their view, the services and laws applicable to persons with mental health problems are equal to those applicable to persons with physical health problems. Many participants were able to cite examples in their society where services and legal protections available to people with physical conditions were not available or less readily available to those with mental health conditions. A member of the focus group in Nigeria noted that much of the country's legislation does not

clearly apply to mental illness; and a participant in a Bangalore focus group pointed out that the Indian policy of job reservation quotas for persons with disabilities does not apply to those with mental health problems. In the United Kingdom focus group several participants thought that their country's rights protection legislation did not adequately cover the rights of people with mental health problems.

Significantly, when participants said that they were unaware of the social services available to people with disabilities, or the precise coverage of laws designed to protect their rights, they still did not hesitate to say that the policies and laws of their culture make a distinction between physical and mental health conditions. They cited differences in restrictions on the right to vote, run for office, or own property. The clear difference in social attitudes, they believed, made it self-evident that there would also be a difference in social policy and law.

### *Social disapproval or stigma*

The data indicate that the majority of individuals in public and in the workplace avoid individuals with disabilities, and find it difficult to work with them. This discomfort increases significantly with mental conditions, and is very high with alcohol- and drug-related health problems. There is some individual variability, but for the most part persons with disabilities face high levels of workplace discrimination and avoidance. It was noted in focus groups that the families of individuals with disabilities often face the same stigma and avoidance. The disabled individual's prospects of marriage are greatly diminished and in those societies where marriage has retained many of its traditional function, other children in the family may also be denied the opportunity of an advantageous marriage.

In the CAR study, key informants were asked questions about a collection of health conditions and disabilities that would elicit data about their perception of the degree of social disapproval that individuals with these conditions would be likely to encounter in their culture. For comparison other, socially visible conditions or states were added: not being able to hold down a job, being dirty and unkempt, not taking care of one's children, having a criminal record for burglary, and being pregnant. Then questions were asked to elicit cultural information about expectations of what activities people with various disabilities should engage in and the likelihood that they would face social barriers to participation. The aim throughout was to operationalize stigma in ways that are relevant to disability.

### Ranking of social disapproval

Key informants were first asked to report their understanding of the degree of social disapproval or stigma that people with various health conditions would encounter in their culture. Eighteen Likert-type rating scales were used to assess the level of negative reaction experienced by someone with each condition. The scales ranged from 0 (no social disapproval) to 10 (extreme). The 18 conditions are listed in Table 9.

Mean ratings of social disapproval were calculated for each condition. Since there was variation between sites in the actual ranges informants used in their assessments, the results are presented in terms of a relative ordering for each society. Across societies, those in wheelchairs, those who were blind, and those who could not read received the least amount of social disapproval, while those with alcoholism, a criminal record, HFV infection, or drug addiction received the highest level of disapproval.

Substantial differences in ordering were found in social disapproval ratings for obesity. In relative terms, obesity drew more stigma in Canada, Turkey, and the United Kingdom, and less in China, Greece, India, and Japan. Depression drew relatively high stigma in Japan and Tunisia, but relatively low stigma in China, Romania, Spain, and the United Kingdom. Being unable to hold down a job drew relatively less stigma in Japan, while homelessness was especially stigmatized in Canada, The Netherlands, and Romania. Leprosy drew a relatively high stigma in Nigeria and China, but low stigma in Tunisia. In Nigeria, leprosy was more stigmatizing than in Egypt and Tunisia. The social disapproval level for someone who does not take care of his or her children was relatively low in Turkey and Japan, but high in Egypt, Luxembourg, and Tunisia.

When each country's ranks are compared with the overall rank order, it can be seen that in Canada, obesity, homelessness and not taking care of children faced more disapproval, while alcoholism was met with relatively less social disapproval. In China, obesity, depression and not taking care of one's children are conditions that were less stigmatizing, whereas leprosy was relatively more stigmatizing. In Egypt, depression was regarded as relatively more, and homelessness relatively less, stigmatizing. In Greece, those in wheelchairs face more disapproval, and the obese face less disapproval. Japan's stigma ordering shows that those in wheelchairs, who are blind, or who have depression or a chronic mental disorder face more disapproval. On the other hand, those who are obese, have a facial disfigurement, are dirty and unkempt, or do not care for their children may trigger relatively less negative reaction in Japan. In Nigeria, those with a chronic mental disorder or leprosy seem to face more social disapproval. In Tunisia, depression was considered

Table 9. Degree of social disapproval or stigma relative ordering from lowest to highest mean rating within each country

Condition (in rank order of total sample)	Country													
	Canada	China	Egypt	Greece	India	Japan	Luxembourg	The Netherlands	Nigeria	Romania	Spain	Tunisia	Turkey	United Kingdom
Wheelchair bound (1)	2	3	1	5	2	5	2	2	1	3	2	1	1	2
Blind (2)	1	5	2	2	4	9	1	1	3	1	1	2	3	1
Inability to read (3)	6	6	3	3	1	2	5	3	2	5	4	5	2	6
Borderline intelligence (4)	3	4	4	7	5	7	3	4	5	7	5	7	6	4
Obese (5)	9	1	5	1	3	1	4	7	4	4	6	3	14	11
Depression (6)	5	2	10	4	6	15	6	6	9	2	3	12	5	3
Dementia (7)	4	8	7	6	9	10	9	8	7	8	7	4	9	5
Facial disfigurement (8)	7	7	8	8	8	3	7	10	6	6	8	9	8	7
Cannot hold down a job (9)	10	11	12	10	10	4	8	9	11	10	11	11	7	10
Homeless (10)	16	9	6	9	7	12	13	15	8	16	10	8	12	8
Chronic mental disorder (11)	12	13	11	12	14	17	10	8	15	9	9	10	10	12
Leprosy (12)	11	16	9	15	13	11	11	11	18	13	14	6	13	9
Dirty and unkempt (13)	15	14	13	11	12	8	12	12	12	12	13	13	11	14
Does not take care of own children (14)	18	10	16	14	11	6	16	14	10	11	15	17	4	17
Alcoholism (15)	8	12	15	13	15	14	15	16	13	14	12	14	17	15
Criminal record for burglary (16)	13	17	17	16	16	13	17	17	17	18	16	15	15	16
HIV positivity (17)	14	18	14	18	17	16	14	13	14	15	18	16	16	13
Drug addiction (18)	17	15	18	17	18	18	18	18	16	17	17	18	18	18
N	15	15	16	15	47	18	16	13	15	15	18	15	15	12

Note: Ranking of 1 indicates least stigma, ranking of 18 indicates most stigma

more stigmatizing than many other conditions, including dementia; leprosy was less stigmatizing than the average. In Turkey, the item "not taking care of one's children" did not provoke as much disapproval, whereas obesity drew relatively more. In the United Kingdom, obesity elicited more social disapproval than many other conditions, while being HIV-positive elicited relatively less social disapproval. India, Luxembourg, Romania, and Spain seemed to have mean orderings on stigma similar to the overall sample.

The sample of informants as a whole clearly indicated that physical disabilities - e.g., being confined to a wheelchair or being blind - carry the least social disapproval. The Japanese data deviated most substantially from this, but even here the conditions remain in the top half of the ordering. Infectious diseases that are potentially deadly or disfiguring - HIV and leprosy - drew considerably more disapproval, and are generally in the bottom half of the ordering, though leprosy elicited less disapproval in Turkey and the UK. A plurality of mental impairments or disorders - borderline intelligence, depression, and dementia - drew only moderate stigma, being generally in or near the top half of the ordering (depression is more stigmatized in Japan). Chronic mental disorder is at or below the middle of the list in most countries, and particularly stigmatized in Japan, Nigeria, and India.

Alcoholism and drug addiction were mostly strongly stigmatized (near the bottom of the list except for alcoholism in Canada) ranking with or below highly stigmatized social characteristics such as homelessness, being dirty or unkempt, or a criminal record for burglary.

The mean orderings on stigma in Table 9 in cultures with a close kinship - e.g., the UK, and Canada, and Luxembourg, and The Netherlands - were often similar. But otherwise it is difficult to discern clear clusterings of response. For instance, there is no clear differentiation in orderings between developing and developed societies.

Reactions to appearing in public

Informants were asked about public reaction to people with certain conditions appearing in public (e.g., on a bus, or in a store or market). The 10 conditions asked about are listed in Table 10. The six response options were:

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



Table 10 Public reaction, ordering from lowest to highest mean rating within each country

Condition (in rank order of total sample)	Country										United King- dom			
	Canada	China	Egypt	Greece	India	Japan	Luxem- bourg	The Nether- lands	Nigeria	Romania		Spain	Tunisia	Turkey
A woman in her 8th month of pregnancy (1)	1	1	5	1	1	2	1	1	1	2	1	4	4	1
Someone who is blind (2)	3	4	4	2	4	3	3	3	4	6	3	2	2	2
A person in a wheelchair (3)	2	5	3	5	5	4	2	2	2	3	2	3	5	3
An obese person (4)	5	2	2	3	2	6	4	4	3	1	5	1	9	4
A person who is intellectually "slow" (5)	4	3	1	4	3	9	5	5	5	4	4	5	7	5
Someone with a face disfigured from burns (6)	6	6	6	6	6	1	6	6	6	5	6	7	3	6
Someone with a chronic mental disorder who "acts out" (7)	7	8	7	8	8	8	7	9	7	8	8	6	1	7
Someone who is dirty and unkempt (8)	8	7	8	7	7	5	8	7	8	7	7	8	6	8
Someone who is visibly drunk (9)	9	9	9	9	9	7	9	8	9	9	9	9	8	9
Someone who is visibly under the influence of drugs (10)	10	10	10	10	10	M	10	10	10	10	10	10	M	M
N	15	15	16	15	47	18	16	13	15	15	18	15	15	12

Note The question was "Please indicate how people in this society would react to a person with the health condition appearing in public." A public reaction score is based on ratings from 1 ("People would think there was no issue, and would pay no attention") to 6 ("People would think it was wrong, and would try to stop it").  
M=missing data, item not included in questionnaire.

In the analysis below, these six responses are treated as an interval scale, with a higher score indicating a greater disapproval of a public appearance.

Again, generally speaking, it is apparent that being in a wheelchair and being blind, along with being eight months pregnant, are not met with disdain in the public eye. Also consistent with the previous section is the finding that being dirty and unkempt, and being either visibly drunk or on drugs in public were likely to be considered "wrong" in some respect across cultures.

There is some variation in the rank orderings. In Egypt, for instance, a woman appearing in public in her eighth month of pregnancy received more criticism than, say, a person who is intellectually "slow." Similarly, in Tunisia being pregnant and appearing in public was slightly more "taboo." In Japan, someone who is "intellectually slow" would be relatively less accepted when appearing in public than elsewhere, while someone who is disfigured from burns would be more accepted. In Romania, someone who is blind would receive relatively harsher reactions for appearing in public. In Turkey, again, an obese person would be less accepted when appearing in public, while someone with a mental disorder who "acts out" would be relatively more accepted than elsewhere.

Table 11 presents a closer look at the extreme end of the distribution, showing the proportion of informants who felt that "people would think it was wrong" for the person with each condition to appear in public. As the relative rankings in Table 10 suggest, there is considerable variation in Table 11 between cultures in the proportion reporting that people "would think it wrong" for an obese person to appear in public. Other conditions showing substantial disagreement between cultures include someone whose face is disfigured from burns, someone who is intellectually "slow," and someone with a chronic mental disorder who "acts out." Japan, Canada, Turkey, and The Netherlands appear more tolerant than other cultures of someone who is visibly drunk or someone who is dirty and unkempt appearing in public. Only for someone who is visibly under the influence of drugs did a majority of informants in the sample say that "people would think it was wrong" to appear in public; Canada and The Netherlands also reported more tolerance than elsewhere for someone with this condition.

Level of surprise at and presence of social barriers

Key informants were presented with five scenarios designed to explore the presence of social barriers, based on whether or not people would be surprised that individuals with different conditions were engaged in specific activities. The scenarios included:

1. A person who confined to a wheelchair because of a spinal cord injury
2. A person born with low intelligence
3. A person who says there are voices talking to him or her all the time
4. A person who is in a bar constantly with a drink in hand
5. A person who is constantly under the influence of heroin

In order to gauge cultural expectations of what activities people with such health conditions can perform, informants were asked, for each of 10 activities: "How surprised would people be if this person did this activity?" Response options were "Not at all surprised," "A little surprised," "Surprised," and "Very surprised." Informants were also asked: "Is it likely that anyone would place restrictions or barriers on the person doing this?" Response options were "Very unlikely," "Somewhat unlikely," "Somewhat likely," and "Very likely."

Table 12 presents the overall percentages, aggregated across all sites, of the respondents who would be surprised (or very surprised) if they saw or heard about someone with a health condition doing the activities listed, as well as the likelihood that barriers would be encountered. There are substantial variations between different activities. Taking public transportation and having sex are activities which would be particularly surprising for someone in a wheelchair, but not for someone with any of the other conditions. A person born with low intelligence is believed to be likely to face barriers with regard to performing most of the 10 activities. The majority of respondents indicated that they would be surprised if someone who hears voices kept a full-time job or became elected to a government position.

A majority of respondents across countries indicated that someone with an alcohol or heroin problem would be unlikely to keep things tidy, take on parenting roles, keep a full-time job, or hold a position in local government. In addition, according to most respondents, persons with such problems would be likely to face some type of barrier in taking part in community festivals, becoming a parent, managing money, keeping a job, or becoming elected.

In Table 13 the ordering of the five conditions for "surprise" and "likely to face barriers" for each site is presented. These orderings are based on average scores calculated across all 10 activities for each country. For the sample as a whole, a person in a wheelchair ranked lowest on both "surprise" and "barriers faced," whereas a person who hears voices ranked highest. Canada is most notably different with respect to a person with an alcohol problem (which ranks in Canada as provoking the least surprise and facing the least barriers), and somewhat different for the low intelligence health condition. In China, persons with alcohol or heroin problems fared the worst. In Greece, people with mental

Table 11 Public reaction: percentage responding "People would think it was wrong" for a person to appear in public, by country

Condition	Total %	Country													
		Canada	China	Egypt	Greece	India	Japan	Luxemb- bourg	The Nether- lands	Nigeria	Romania	Spain	Tunisia	Turkey	United King- dom
A woman in her 8th month of pregnancy	2	0	0	0	0	4	0	0	0	7	0	0	0	7	0
Someone who is blind	3	7	0	0	0	6	0	0	0	7	13	0	0	0	0
A person in a wheelchair	2	0	0	0	13	7	0	0	0	0	0	0	0	0	0
An obese person	12	20	7	13	7	6	19	31	8	13	0	17	0	20	8
A person who is intellectually "slow"	7	7	0	0	0	4	23	0	0	13	0	0	14	33	8
Someone with a face disfigured from burns	6	0	33	6	0	0	0	12	0	20	0	0	13	7	0
Someone with a chronic mental disorder who "acts out"	15	0	33	0	20	17	12	19	17	13	27	22	0	0	17
Someone who is dirty and unkempt	25	20	27	69	20	17	0	44	8	47	40	17	43	0	33
Someone who is visibly drunk	46	13	27	88	27	46	6	81	8	80	73	50	79	14	50

Someone who is visibly under the influence of drugs	58	20	57	100	40	67	M	56	17	64	67	56	79	M	M
<i>N</i>	245	15	15	16	15	47	18	16	13	15	15	18	15	15	12

Note: The question was "Please indicate how people in this society would react to a person with the health condition appearing in public." "Think it was wrong" refers to responses: "People would think it was wrong, and might say something about it" and "People would think it was wrong and try to stop it."  
M=missing data; item not included in questionnaire.

Table 12. Surprise that a person with a health condition performs an activity, and likelihood that a person would face barriers (*N*=245)

Country	Health condition				
	Person in wheelchair	Person born with low intelligence	Person who hears voices	Person with alcohol problem	Person with heroin problem
Keeping things tidy					
Would be surprised	48	19	46	66	67
Likely to face barriers	43	15	32	24	26
Using public transportation					
Would be surprised	55	13	23	15	17
Likely to face barriers	49	28	45	37	39
Being in love					
Would be surprised	25	25	44	21	22
Likely to face barriers	45	53	62	46	50
Having sex (as part of a relationship with someone)					
Would be surprised	50	26	34	12	14
Likely to face barriers	45	56	59	38	42
Actively taking on parenting roles					
Would be surprised	28	48	60	49	64
Likely to face barriers	32	55	69	54	68
Actively taking part in community fairs and festivals					
Would be surprised	23	21	40	37	42
Likely to face barriers	26	32	58	55	60
Managing own money					
Would be surprised	6	68	40	37	42
Likely to face barriers	20	74	54	56	62

Getting an apartment or somewhere to live	18	46	42	24	36
Would be surprised	33	58	56	37	51
Likely to face barriers					
Keeping a full-time job	31	40	65	62	79
Would be surprised	39	49	72	65	73
Likely to face barriers					
Being elected or named to a position in local government	44	86	86	76	90
Would be surprised	49	86	88	82	90
Likely to face barriers					

Note: The questions and included responses were "How surprised would people be if this person did this activity?" - "Surprised" and "Very surprised"; and "Is it likely that anyone would place restrictions or barriers on the person doing this?" - "Somewhat likely" and "Very likely."

health problems (low intelligence, hears voices) seem to face the most obstacles. A person in a wheelchair in India and Nigeria was perceived as least likely to carry out the given activities, relative to the other conditions. In Egypt, Japan, Nigeria, Spain and Turkey, a person with a heroin problem seemed to be most likely to face barriers. In The Netherlands and Romania, this can be said for a person with low intelligence.

As already noted, issues of social disapproval and barriers to social participation were approached in the key informant interviews from several angles. In Table 14, the patterning of responses on these questions concerning each of five health conditions are summarized in terms of the relative ranking of the five conditions. This reflects the comparative emphasis of this analysis, and also steers around the apparent differences in the tacit systems of measurement used by informants at different sites.

Averaging across all sites, the person in a wheelchair - the physical health problems used as an index condition - was viewed as the least stigmatized and the most socially accepted to appear in public of the five conditions. In terms of social and daily-life activities, participation by the person in a wheelchair would also overall be the least surprising, and would meet the fewest restrictions or barriers. Second in terms of less stigmatization and more acceptance of appearing in public was the person with low intelligence, followed in order by the person with a chronic mental disorder, the person with an alcohol problem, and the person with a heroin problem. The ordering on participation in social and daily-life activities was somewhat different, with the person with an alcohol problem ranking second, the person with low intelligence third, and the person with a chronic mental disorder last.

In terms of the relative stigma of the five conditions, a majority of societies - Greece, India, Luxembourg, The Netherlands, Romania, Spain, Tunisia, Turkey, and the United Kingdom - followed the ranking of the average across sites. The other societies - Canada, China, Japan, and Nigeria - showed a minor deviation in ordering, the person with an alcohol problem less stigmatized than the person with a chronic mental disorder. In general, the convergence in the ordering of stigma among the conditions was impressive.

A number of societies - Canada, Luxembourg, Nigeria, Romania, Spain, Tunisia, and the United Kingdom - followed the same rank order as the average ranking across all sites for acceptance of the person with the condition appearing in public. For answers to this question, deviations in ordering were more varied. In China, Greece, and India, more acceptance was reported for a person with low intelligence appearing in public than for a person in a wheelchair. In Japan and The Netherlands, a person with an alcohol problem ranked higher than elsewhere on appearing in public. A person with

Table 13. Ordering of five health conditions by "People would be surprised" and "They would be likely to face barriers"

Country		Health condition				
		Person in wheelchair	Person born with low intelligence	Person who hears voices	Person with alcohol problem	Person with heroin problem
Total	(order on) Surprised	1	3	5	2	4
Sample	(order on) Likely to face barriers	1	3	5	2	4
Canada	(order on) Surprised	2	4	5	1	3
	(order on) Likely to face barriers	3	4	5	1	2
China	(order on) Surprised	2	1	3	4	5
	(order on) Likely to face barriers	1	2	3	5	4
Egypt	(order on) Surprised	1	3	5	2	4
	(order on) Likely to face barriers	1	2	4	3	5
Greece	(order on) Surprised	1	5	4	2	3
	(order on) Likely to face barriers	1	4	5	2	3
India	(order on) Surprised	4	1	5	2	3
	(order on) Likely to face barriers	1	2	5	3	4
Japan	(order on) Surprised	1	4	3	2	5
	(order on) Likely to face barriers	1	3	4	2	5
Luxembourg	(order on) Surprised	1	3	5	2	4
	(order on) Likely to face barriers	1	3	5	2	4
The Netherlands	(order on) Surprised	3	5	4	1	2
	(order on) Likely to face barriers	1	5	3	2	4
Nigeria	(order on) Surprised	3	1	4	2	5
	(order on) Likely to face barriers	2	1	4	3	5
Romania	(order on) Surprised	1	5	2	3	4
	(order on) Likely to face barriers	1	4	2	5	3
Spain	(order on) Surprised	1	2	4	3	5
	(order on) Likely to face barriers	1	2	4	3	5
Tunisia	(order on) Surprised	1	2	5	3	4
	(order on) Likely to face barriers	1	2	5	3	4
Turkey	(order on) Surprised	1	4	2	3	5
	(order on) Likely to face barriers	1	4	2	3	5
UK	(order on) Surprised	1	2	5	3	4
	(order on) Likely to face barriers	1	4	5	2	3

Note: The questions asked were "How surprised would people be if this person did this activity?" and "Is it likely that anyone would place restrictions or barriers on the person doing this?" Ordering is based on means. 1 = least surprised, and least likely to face barriers.

Table 14. Social disapproval, expectation of social participation, barriers to social participation: ordering of 5 health conditions

Country	Health condition				
	Person in wheelchair	Person born with low intelligence	Person who hears voices	Person with alcohol problem	Person with heroin problem
Total sample (N=204)					
Degree of stigma (1=less)	1	2	3	4	5
Public appearance (1=OK)	1	2	3	4	5
Participation expected (1=more)	1	3	5	2	4
Participation barred (1=less)	1	3	5	2	4
Canada (N=15)					
Degree of stigma (1=less)	1	2	4	3	5
Public appearance (1=OK)	1	2	3	4	5
Participation expected (1=more)	2	4	5	1	3
Participation barred (1=less)	3	4	5	1	2
China (N=15)					
Degree of stigma (1=less)	1	2	4	3	5
Public appearance (1=OK)	2	1	3	4	5
Participation expected (1=more)	2	1	3	4	5
Participation barred (1=less)	1	2	3	4	5
Greece (N=15)					
Degree of stigma (1=less)	1	2	3	4	5
Public appearance (1=OK)	2	1	3	4	5
Participation expected (1=more)	1	5	4	2	3
Participation barred (1=less)	1	4	5	2	3
India (N=47)					
Degree of stigma (1=less)	1	2	3	4	5
Public appearance (1=OK)	2	1	3	4	5
Participation expected (1=more)	4	1	5	2	3
Participation barred (1=less)	1	2	5	3	4
Japan (N=18)					
Degree of stigma (1=less)	1	2	4	3	5
Public appearance (1=OK)	1	4	3	2	-
Participation expected (1=more)	1	4	3	2	5
Participation barred (1=less)	1	3	4	2	5
Luxembourg (N=16)					
Degree of stigma (1=less)	1	2	3	4	5
Public appearance (1=OK)	1	2	3	4	5
Participation expected (1=more)	1	3	5	2	4
Participation barred (1=less)	1	3	5	2	4
Romania (N=15)					
Degree of stigma (1=less)	1	2	3	4	5
Public appearance (1=OK)	1	2	3	4	5
Participation expected (1=more)	1	5	2	3	4
Participation barred (1=less)	1	4	2	5	3
Spain (N=18)					
Degree of stigma (1=less)	1	2	3	4	5
Public appearance (1=OK)	1	2	3	4	5
Participation expected (1=more)	1	2	4	3	5
Participation barred (1=less)	1	2	4	3	5
Tunisia (N=15)					
Degree of stigma (1=less)	1	2	3	4	5
Public appearance (1=OK)	1	2	3	4	5
Participation expected (1=more)	1	2	5	3	4
Participation barred (1=less)	1	2	5	3	4
Turkey (N=15)					
Degree of stigma (1=less)	1	2	3	4	5
Public appearance (1=OK)	2	3	1	4	5
Participation expected (1=more)	1	4	2	3	5
Participation barred (1=less)	1	4	2	3	5
United Kingdom (N=15)					
Degree of stigma (1=less)	1	2	3	4	-
Public appearance (1=OK)	1	2	3	4	-
Participation expected (1=more)	1	2	5	3	4
Participation barred (1=less)	1	4	5	2	3

low intelligence ranked lower than elsewhere on this dimension in Japan and Turkey. In Turkey, indeed, public appearance was reported to be most accepted for the person with a chronic mental disorder.

The responses from Canada were unique in ranking the person with an alcohol problem lowest both on surprise at, and on restrictions and barriers to, social participation. Other societies where the person with alcohol problems ranked relatively low on these dimensions included The Netherlands and Greece. On the other hand, it was reported that in China and Romania the person with alcohol problems would find the most restrictions on social participation, even greater than for the person with a heroin problem.

Altogether, in seven societies the person with a heroin problem was ranked lowest or next to lowest on social participation expectations and resistance, while this person would be met with relatively less surprise and resistance, it was felt, in Canada and The Netherlands. In most societies, social participation by the person in a wheelchair would be greeted with the least surprise and resistance. The surprise would be relatively greater in India and Nigeria; only in Canada and Nigeria were the restrictions or barriers on participation expected to be less for another condition than for the person in a wheelchair.

Overall, the ordering of the five conditions showed considerable variations across dimensions and across sites. Nevertheless, some general patterns emerge. Both on stigma and on expectations of participation, the person in a wheelchair is generally regarded the most favourably. For stigma, the persons with alcohol and heroin problems usually rank high, while for expectations and restrictions on participation, it is the person with a chronic mental disorder and the person with a heroin problem who generally vie for the least favourable position.

## Summary and conclusions

The centre report, focus group, and key informant data made a significant contribution to the CAR study's ability to explore both cross-cultural comparability of views on disability, and the significant differences in the ways that individual societies attached stigma, evaluated the need for assistance, noticed the problem in the first place, and attached evaluations of severity to different kinds of health conditions. The results strongly indicated that the model of disability found in ICDH-2 is sufficiently cross-culturally applicable to justify the continued development and dissemination of the international classification, and they solidly supported the current and future work on creating an international "language of disability."

The following chapter explores the structure of the classification of disabilities, and the specific concepts behind the conceptualization of disability that have been implicit in this chapter.