

Chapter 1

Disability and Cultural Variation: The ICDH-2 Cross-Cultural Applicability Research Study

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Background to the ICDH

Over the last three decades or so there has been a gradual shift in the conceptualization of health and disability. The focus has moved away from diagnosis alone towards an understanding of the consequences of health conditions in terms of disabilities that are experienced at the level of the body, the person and the overall social context. In addition, the subjective components of a health experience ("quality of life," "subjective well-being") have also acquired legitimacy in the understanding of all aspects of health and its consequences. It is therefore no longer sufficient and defensible to look merely at diagnosis to seek to understand the full breadth of the health experience; instead, functioning, disability and the quality of life must also be examined. Moreover, we now appreciate that health experiences, because they occur in a specific context, cannot be divorced from environmental and personal factors that may differ from one geographical location to another.

In recognition of this change, the World Health Organization (WHO) has over the last decade and a half been engaged in a comprehensive exercise of developing instruments for the diagnosis and classification of alcohol, drug and mental (ADM) disorders that can be used cross-culturally and internationally. This work is part of a joint collaborative project between WHO and the United States National Institutes of Health (NIH) – in particular the National Institute of Mental Health (NIMH), the National Institute on Alcohol

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Abuse and Alcoholism (NIAAA), and the National Institute on Drug Abuse (NIDA) – on the assessment and classification of ADM disabilities. In the first phase of this collaboration, the focus was on the development of a revised version of the mental and substance use disorders classification for Chapter V of the 10th revision of the *International Classification of Diseases* (WHO 1992), as well as the development of assessment instruments linked to both the ICD-10 and the *Diagnostic and Statistical Manual of Mental Disorders* (DSM) (American Psychiatric Association 1994).

The second phase of the WHO-NIH joint project was based on the recognition that diagnosis alone does not predict many of the important health care and service planning outcomes that health planners need to know in order to make informed judgements about resource allocation and cost-effectiveness. Diagnosis supplemented by information about the dimensions of functioning and disability, however, can predict health care utilization, needs, outcomes and costs. What is needed, therefore, and what this phase of the joint project will provide, are disability assessment instruments that are cross-culturally applicable and linked to a clear conceptual framework.

WHO has also been involved over the last five years in the revision of a classification of disability and human functioning called the *International Classification of Impairments, Disabilities and Handicaps* (ICIDH), first published in 1980 (WHO 1980). The ICIDH-2 – the full name of which will likely be the *International Classification of Functioning and Disability* – will be presented to the World Health Assembly for approval in 2001.

One of the key concerns in the ICIDH-2 revision process has been systematically to examine issues surrounding the impact of ADM disorders as measured by the extent of disability caused by these conditions. The recent recognition that, if morbidity and disability are taken into account, ADM disorders constitute a major burden on society – far surpassing conditions that kill such as HIV/AIDS and cancer – has catapulted ADM disorders into prominence and reopened the debate on whether there ought to be parity of social response between these conditions and other physical illnesses (Murray & Lopez 1996).

The concept of etiological neutrality, embodied in the current understanding of disability experiences and a guiding principle of the ICIDH-2 revision, emphasizes that in principle there need not be predictable correlations between various health conditions and aspects of disability. This means that persons with physical disease conditions may experience the same or different activity limitations and participation restrictions as those with mental disease conditions, so that it is inaccurate and prejudicial to assume that certain forms of disability are inextricably linked to one disease rather than another. A person may be unable to walk around the block

as a consequence of a visual impairment, a spinal injury, a neurosis, or an addiction to drugs.

In addition, disability is now understood to be a complex phenomenon that manifests itself at the body, person or social levels. According to this model, adopted in the revised ICIDH-2, these three dimensions of disability are outcomes of interactions between the health condition and other intrinsic features of the individual and extrinsic features of the social and physical environment. It is therefore always relevant to consider the effect on the disablement process of environmental factors, even when the most appropriate interventions are those aimed directly at person. Thus multiple interventions may be feasible and appropriate. Persons with disabilities may profit from medical and rehabilitative interventions as well as social and political interventions. It is important to appreciate that disability is not an intrinsic or defining feature of a subset of human beings (and as such is not analogous to other human differences such as gender and race), but is a universal condition of humanity itself (Bickenbach, Chatterji, Badley et al. 1999). It is also quite clear that it is inappropriate and scientifically inaccurate to characterize disability in isolation from human functioning, or, for that matter, to characterize disability in inherently negative and depreciatory terms.

It is clearly not enough, however, to create disability classification and assessment tools for one language or for one culture. WHO is committed, not merely to the international dissemination of ICIDH-2 and other epidemiological instruments, but to ensuring their cultural applicability. The uncritical transfer of disability concepts and terminology across diverse languages and cultural settings may produce confusion without a proper understanding of each culture. Therefore, the second phase of the WHO/NIH joint project aimed to develop disability assessment instruments, on the basis of the work being done on the revision of the ICIDH-2, that were applicable in different cultures and could be used to compare international statistics and to better organize health services better. Once again, the motivation for this work, from WHO's standpoint, as health is a universal human concern, scientific tools developed to address health must be applicable transculturally and around the world.

The assessment and measurement of disability has been fraught with several problems. Though people intuitively understand what disability is, the construct has often not been operationally defined and no common standard tools exist. There is considerable confusion in defining the universe of assessment: symptoms and signs, activities of daily living, social support, burden, satisfaction, subjective well-being and quality of life may all be included within the rubric of disability. Theoretical frameworks have spanned activities of daily living (ADL), instrumental activities of daily living (IADL),

social and role functioning, and adaptive functioning. Determination of levels of disability has been confounded by contextual factors such as cultural expectations and the availability of assistive devices, personal help, and environmental modifications and adaptations (Üstün & Chatterji 1998).

Although "disability" is a universally used term, in both everyday language and the professional and scientific literature, it is ambiguous. The term might refer to a functional or structural abnormality at the body level (say, a problem with protein metabolism or a missing leg); or a person level problem in acting or behaving (being unable to dress oneself, or to drive a car); or else a societal level problem of being socially disadvantaged because of functional problems at the body or person level (losing a job or being denied a driver's licence). To avoid confusing these three very different notions, the original ICIDH used the terms "impairment," "disability" and "handicap" to distinguish the three dimensions, with the umbrella term "disablement" covering all three.

Early in the revision process, it was decided that the ICIDH-2 should not be a classification of functional problems that people may experience, but rather a universal classification of human functionality itself, both positive and negative. Because of this, and the importance of expressing the classification in neutral and flexible language, the three levels were relabelled Body Function and Structure, Activity, and Participation. Since the term "disablement" proved to be difficult to translate, and "disability" was now freed from its association with person level functional problems, it was decided to return to "disability" as an overall term for all three levels of functional difficulty. The term "disablement" is kept as a stipulative term naming the interactive process by which the levels of disabilities come about.

The original, 1980 version of the ICIDH was the first attempt at an international, universal common language of disability. It was translated into at least 15 languages and referred to in over 1600 scientific articles. Its extensive use brought to the fore the need, in health outcome classification and assessment, to supplement diagnostic categories with aspects of human dysfunctioning and social disadvantage.

Yet, the ICIDH 1980 was criticized on many grounds. Its classifications were said to be too closely aligned with diseases and disease sequelae, and therefore it was too medical in orientation (Chamie 1995). It was also said that the ICIDH implicitly assumed that the relationship between impairments, disabilities and handicaps was causally ordered (Halbertsma 1995). Further, it was argued that although the role of the social environment in the creation of disabilities and handicaps was noted, the model of disability did not explicitly include environmental factors and so this essential component of the process of disablement was neglected (Fougeyrollas 1995).

Much of the criticism of the ICDH came from researchers who argued that the dimensions of disability, especially handicap, were best conceived as products of the social and built environment, rather than the medical or functional state of the individual. Although the drafters of the ICDH 1980 were certainly conscious of this fact, many argued that the classification was not clear in recognizing that, because of social prejudice or stereotypical attitudes, or just ignorance, people with impairments and disabilities around the world found themselves disadvantaged in many areas of life and unable to participate fully in normal social roles and positions. Inaccessible buildings or the lack of environmental modifications or accommodations contributed to the handicap that individuals experienced; indeed, many argued it was the social and physical environment that "handicapped" people, not their physical or mental condition. Representatives of this approach, often called "the social model of disability," argued that the ICDH was not an adequate basis for research into the dimensions of disability (Shakespeare 1993).

In the early 1990s, WHO brought together a worldwide network of collaborating centres, as well as a wide variety of health professionals, policy-makers and persons with disabilities and their advocacy organizations, to begin the task of revising the ICDH. Coordinated with other United Nations agencies, the process has slowly built up a consensus on a useful and empirically grounded model of disability that synthesizes the medical and the social models to produce a robust and flexible construct that can be employed in many sectors and for many different purposes. A preliminary draft of the ICDH-2 was reviewed in the latter half of 1997, and the comments were then incorporated into a second draft (the "Beta-1 draft") used for field trial purposes. By early 1999 the results of those tests, conducted around the world, were incorporated into another draft, the Beta-2 draft, which was again the basis for another round of field testing.

In brief, the ICDH-2 presents the following picture of disability. All levels of disability occur with a health condition and within the context defined by environmental factors and personal characteristics (age, sex, level of education, life history and so on). The three dimensions of disability are not conceived as links in a causal chain, but as alternative, but conceptually distinct, perspectives on the disablement process. One perspective is at the level of body or body part, and abnormalities of function or structure are called *impairments*. If, in association with a health condition, a person does not perform a range of activities that others perform, this person level difficulty is called an *activity limitation*. Finally, from the perspective of complete context of a person's life, characterized for the most part by the physical and social environment in which the person lives, disability may be manifested as restrictions in major areas of human life – for example, parenting,

employment, education, social interaction and citizenship. In the ICDH-2, these are termed *participation restrictions*.

The conceptual model in the ICDH-2 (see Figure 1) offers a complete picture of the functional aspects of the health experience, understood as an outcome of an interaction between features of the person, on the one hand, and social and physical environmental factors on the other. By incorporating both the medical and the social models of disability, the ICDH-2 provides a flexible classificatory tool that allows users to describe, in an international common language, both medical and rehabilitative phenomena (from the perspective of impairments and activity limitations) as well as consequences of the environment for persons with disabilities with regard to their levels of participation in the full range of human life. Rather than being a classification of persons with disabilities, or even of the problems that they may experience, the ICDH-2 is a classification of functionality at three levels, understood in neutral terms. In this way, the user can identify, not only problems at the level of body, person and society, but also absence of problems and presence of strengths. The ICDH-2 is a universal tool for the classification of functioning and disability.

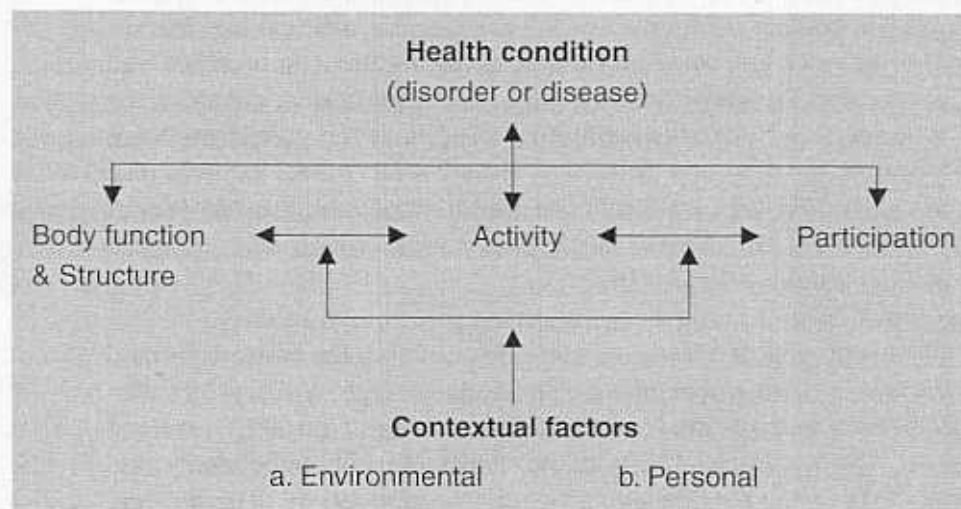


Figure 1. The ICDH-2 model of disability

The study of disability involves a confluence of medical care, rehabilitation, education, and community action as well as law, politics and social science research. The ICDH-2 is designed for these uses in preparation for a new era of disability studies. For it is no longer sufficient to rely on one approach to the exclusion of another. Numbers must be joined to narratives. Social theory must have a place along with health sciences in formulation of

policy. By addressing the local context of the social experience of a health condition and associated disability we have a better chance of improving the quality of life of people. Health policy is thus inseparable from social policy. Innovations in social policy derived from collective experience are necessary to address the needs of local communities. This is the new world of research that the ICIDH-2 anticipates.

Cultural diversity and universality?

There is, however, a fundamental dilemma that poses an obstacle to this research agenda. It is generally agreed that the appropriate aim of a classification tool such as the ICIDH-2 is to provide an international common language, as well as a universal conceptual framework for disability across languages and cultures. Yet the experience of disability is unique to each individual, not only because the precise manifestation of a disease, disorder or injury is unique, but also because the consequences of these health conditions will be influenced by a complex combination of factors, from personal differences in experience, background and basic emotional, psychological and intellectual make-up to differences in the physical, social and cultural context in which that person lives. This fact, moreover, is fundamental to the background model of the ICIDH-2, which sees the process of disablement as fitting within the complete social and physical environment in which a person lives.

Some suggest, however, that a strong case can be made against the possibility of a universal and transcultural common language for all three dimensions of disability. For not only are personal experiences of disability individual and unique, but perception of and attitudes towards disability are highly relative, since they are subject to cultural interpretations that depend on values, contexts, socio-historical time and place, as well as the perspective and social status of the observer. Disability and its social construction accordingly vary from society to society and from time to time. Throughout human history societies have defined the notion of disability and its dimensions in different ways, and these definitions have themselves evolved over time.

Despite this, as noted, the ICIDH-2 revision process is based on the principle that disability is a universal trait of human beings and not a unique identifier of a social group. The principle of universalism entails that all human beings have, either in fact or potentially, some limitation in functionality at the body, person or social level associated with a health condition. Disability is not, in short, a defining feature of a minority of people; it is a universal human trait. Nor is disability a dichotomous status; instead there is

a continuum of levels and degrees of functionality. Disability, in all its dimensions, is always relative to the expectations placed on people's functioning – what they are expected to do and not do. A clear consequence of universalism is that underlying the diversity of manifestations of disability, there must be a core of functional states that are amenable to scientific identification. This underlying commonality is, of course, what ICIDH-2 attempts to classify.

Universalism does not necessarily imply that impairment always and in every society will lead to activity limitations or participation restrictions. To be sure, we have unequivocal evidence from archaeological sites that living with impairment is ubiquitous. Skeletal remains often demonstrate congenital malformations, trauma or arthritic changes. We can assume that these impairments lead to the same or similar kinds of activity limitations wherever they occur. But we also know that it is wrong to assume that impairments or activity limitations cause a person to be automatically marginalized from social groups or to be otherwise disadvantaged by having their participation restricted in some area of life. Though this may be true of a small number of serious impairments and activity limitations such as blindness or paraplegia, these are not representative of the wider domain of disabilities, many of which go unnoticed, or are not socially visible because of coping or accommodation mechanisms.

The variety of roles that people with disabilities occupy is striking. In some communities persons with disabilities are priests, in others they are musicians or artisans. And in yet other societies, they are beggars. When a high percentage of persons with a disability live in a small population, strong cultural traditions often emerge to support the participation of the disabled person in whatever roles the society deems appropriate. People with albinism in the Cuna Indian population in Panama (de Smidt 1948), and the deaf on the island of Martha's Vineyard in the United States (Groce 1985) are examples of small scale societies in which disabled individuals are related and connected to each other through diffuse social roles and contexts.

In short, it may not be possible, anthropologically and in special cases, to generalize from a physical impairment to a single social identity. It might be safe to offer as a hypothesis, however, that in complex societies that stress individualism and achievement, and where social relationships are more impersonal and task-specific, peoples' physical characteristics are more often used to classify people and form their personal identity.

Science, bureaucracy and organized religion have each played an important role in shaping the construction of disability: as the broken, incomplete and imperfect self, as the case requiring management, and as the object of pity and charity. This has led people to argue for a more integrated concep-

tion of self, based not upon an empirical, mechanized and bureaucratic world-view, but upon an integrated, interdependent and holistic view of self and society. In that way a more universal understanding of disability may be possible. At the same time, when we turn to the issue of social attitudes toward disability, and people with disabilities, including the way people report disability and its severity, we are confronted with what appears to be an enormous variation across cultures. Consider these recent studies, and the hypotheses they suggest:

- A study of randomly selected villagers in Vellore in southern India, which examined attitudes towards individuals with physical disabilities, revealed that 82% of these attitudes were positive (Bakheit & Shanmugalingam 1997). Gender and employment status did not appear to have an influence on whether the respondent regarded disabled people in a positive or negative way but most older individuals expressed prejudice or challenged the rights of disabled people to equal opportunities in education, employment and social integration. This suggests that in some contexts and social arrangements disability can be positively valued, a fact that should encourage disability advocates around the world.
- In older Chinese society, the support provided by family members, as well as adequate income to meet living expenses, have been found to play a role equal to that of physical factors in contributing to life satisfaction (Ho, Woo & Lau et al. 1995). This supports the view that background social factors influence the subjective experience of disability.
- Doyle and Wong (1996), in a study of Cantonese-speaking adults, showed that they do not perceive a hearing problem even when screening tests identify hearing loss. Among persons who failed a screening test for hearing, more than two-thirds reported that they had no problems in hearing during conversations. Persons who reported hearing difficulties tended to have meant hearing levels in excess of the screening threshold. In a similar study in rural Egypt examining the experience of blindness, it was found that villagers' assessments of their vision differed substantially from ophthalmic measurements of their vision (Lane, Mikhail, Reizian et al. 1993). Individuals with profound visual loss remained independent in their daily activities and contributed to their families' subsistence. While they agreed that they had "weak eyesight," they did not perceive themselves to be disabled. This suggests that the presence of disability is a function of expectations, which are culturally or socially determined.
- A study of the traditional beliefs and practices concerning leprosy of the Limba people of Sierra Leone showed that their traditional definition of illness holds that a person is seriously ill only when he or she has severe

pain or disability (Opala & Boillot 1996). As a result, they seek help only at relatively advanced stages of the disease. In a study of low-income Puerto Rican parents whose children were classified as learning-disabled or mildly mentally retarded, it was shown that cultural meanings of disability and normalcy may lead parents to reject the very notion of disability (Ruiz 1995). The parents focused instead on the impact of family identity, language confusion, and detrimental educational practices as causes of their children's school performance. Thus the threshold of what constitutes a disability may be determined by cultural expectations.

- Considerable differences between concepts of disease, disability and well-being between Bengalis and Somalis living in the United Kingdom have been documented (Silveira & Ebrahim 1995). In study on epilepsy in Zimbabwe and the USA, Devlieger, Piachaud and Leung (1994) showed that coping skills in a group of Zimbabweans tended to be related to the experience of "being different," while in the Midwestern US group "not being able to do things" was a major experience. When the study linked coping mechanisms to the cultural environment, two major cultural influences in Zimbabwe stood out as being different from the Midwest: the belief in external control and cause of mental and physical health; and cultural conflict. These studies indicate that subcultural influences may be more determinative of attitudes about disabilities than the larger, national cultural views.
- In several studies using standard functional assessment tools, which purport to measure universal phenomena, substantial cultural divergence has been noted. Studies using the Functional Impairment Measure (FIM) in different parts of the world have shown that, for example, item difficulty patterns in Japan differ slightly from those in the United States because of cultural differences (Tsuji, Sonoda, Domen, et al. 1995). Studies using "standard" instruments used by the Office of Population, Census and Surveys (OPCS) and instruments to measure activities of daily living (ADLs) and instrumental activities of daily living (IADLs) have shown similar variability. In a study in Thailand using the OPCS interview, the disability score of 4.8 (1.9) with a range of 0-10 was found to be unsuitable because of misinterpretation of behavioural and intellectual disability leading to 99% of subjects being scored as disabled (Jitapunkul, Kamolratanakul & Ebrahim 1994). A study in Taiwan questioned whether activities can be calibrated on the same scale as North American activities to make a single cross-cultural ADLs (Fisher, Liu, Velozo, et al. 1992). All of these studies cast doubt on claims of generalizability of functional assessment.

- A study of health practitioners from the Chinese, Italian, German, Greek, Arabic and Anglo communities in Australia used social distance scales to rate the attitudes of people in their communities toward 20 disability groups (Westbrook, Legge & Pennay 1993). Significant differences were found in community attitudes towards people with 19 of these disabilities. Overall the German community expressed greatest acceptance of people with disabilities, followed by the Anglo, Italian, Chinese, Greek and Arabic groups. However the relative degree of stigma attached to the various disabilities by the communities was very similar. In all communities, people with asthma, diabetes, heart disease and arthritis were the most accepted and people with AIDS, mental retardation, psychiatric illness and cerebral palsy, were the least accepted of the disability groups. This suggests that patterns of attitudes may be tracked, and to some extent generalized.
- A study of visual disability among Hamar men in Ethiopia revealed that even mild visual disability is less common in men (Courtright, Klungsoyr & Lewallen, et al. 1993). In Hamar society men have two roles, those of herders or warriors. Warriors with visual loss will be less successful in defending themselves. The study suggested that Hamar men who develop visual loss have increased mortality compared to women with visual loss. Vision loss in women does not appear to have life-threatening consequences. This is sometimes called the phenomenon of "spread" in which social roles extend, or constrain, the level of disability experienced and reported by individuals.

These and other studies appear to argue against the possibility of a universal, transcultural classification of disability, such as the ICIDH-2 purports to be. There seems as well to be support in this from studies in medical anthropology that suggest that many health and illness concepts are variable across cultures and sub-cultures (for example, the studies of Bice & Kalimo 1971, Scheer & Groce 1988, Pezza 1991, Weller et al. 1991, and Yoder & Hornick 1996)

Recently, the denial of the possibility of universality in the case of disability was explicitly made by Benedicte Ingstad and Susan Reynolds Whyte in one of the first collections of anthropological studies explicitly focusing on the social perception of disability. Ingstad and Whyte (1995) claim that, in their view, "attempts to universalize the category 'disabled' ran into conceptual problems of the most fundamental sort." They argue that the supposition that universal definitions and classifications of disability are possible is itself a culturally determined view, associated with North American and European societies with their strong attachment to universalistic biomedical sciences, on the one hand, and individualistic conceptions of personhood on the other.

There does indeed appear to be evidence from anthropology and medical sociology that cultural beliefs affect how health care professionals and people with disabilities interpret health, illness and disability. Cultural beliefs cause people to learn "approved" ways of being ill, influence their attribution of the etiology of illness or disability, and determine what they expect from treatment and their physicians and other health professionals. Consequently, health professionals need to be aware of cultural differences that can affect the outcome of treatment. Yet why should this fact undermine the possibility, let alone the usefulness, of an international classification of disability? Some researchers would reject outright the view that cultural difference on its own can be interpreted as grounds for doubting the existence of underlying, objective and transcultural disability phenomena. These unrepentant positivists would argue that cultural differences are irrelevant, or at least should not stand in the way of producing a universal classification instrument. However, this is too extreme a reaction to the concerns of anthropologists and others.

At least two other reactions are possible. Following Ingstad and Whyte, we might distinguish between "weak" and "radical" relativism. The weak version asserts that the relationship between the dimensions of disability is relative to the context in which the disability is manifested: cultural variation, as well as climatic and physical environmental variation, will contribute to the disabling consequences of similar impairments. This being so, the weak relativist would argue, it is dangerous to generalize associations or linkages between the dimensions of disability. The weak relativist would also argue that, while the basic concepts of disability may be universal, the linguistic expression of these concepts will vary, perhaps dramatically, across cultures and languages. There is no reason to assume, for example, that every language will make the kinds of distinctions between levels of visual acuity that are found in European languages, simply because some levels of low vision are not detectable, or socially remarkable. At the extreme (complete blindness), the phenomenon will undoubtedly be expressible in every language, although whether that is so remains an empirical question awaiting research.

For the weak relativist, any attempt to create an international and purportedly transcultural classification of disability must be approached with caution, since the temptation will be great to assume far less linguistic and cultural variation than there may be. Being aware of linguistic and cultural difference is an essential requirement of the development of a universal classification system. In principle, a classification that is interlinguistically and interculturally applicable is a possibility, although certainly not something achieved without considerable sensitivity and effort.

It is precisely this possibility, however, that the radical relativist rejects. According to this view, the very existence of disability concepts, not merely their linguistic or cultural applicability, is a social construction, highly relative to culture and historical period. For the radical relativist, no universal conceptualization of disability is justifiable since we cannot presume that any disability concept (let alone the overall conceptualization of disability) applies, or even makes sense, in all cultures around the globe. Different cultures "construct" disability differently (or not at all), and there is no reason to think that these differences are commensurable, intertranslatable, or intelligible between cultures.

The key issue in this debate is not so much who is right, but whether it is possible, empirically, to determine which position is more plausible. On some interpretations, the radical relativist position is non-falsifiable: no evidence is in principle available to confirm or deny the position since it is a moral or political stance disguised as a scientific hypothesis. If, however, the radical position were amenable to empirical evidence, how could we proceed?

The radical relativist may reject this question from the start. Asking for empirical evidence, he or she may insist, is itself a reflection of a particular worldview that need not be shared. Moreover, any empirical method proposed to settle the issue might be thought to prejudge the radical relativist position. If this is the view, however, the debate between the relativist and others must grind to a halt, not because the radical relativist has won a victory, but because nothing more can be said. The price paid for the end of the debate, moreover, is very high. If we cannot move the debate forward, then we cannot begin to address the genuine social issues of unmet health needs, discrimination and other forms of social disadvantage. This version of the radical relativist position leads only to social stagnation and the *status quo*.

There is no reason to abandon hope. On the face of it, it is not implausible to argue that, despite linguistic and cultural differences, a transcultural understanding of disability is possible. First of all, few have argued, or presented evidence, that impairments (abnormalities of bodily structure or function, based on biomedical norms) are radically relative. Most commonly, the radical relativist will claim that it is the manifestation of impairments in the lives of people that is relative. At the same time, though, if it is understood that disabilities are concerned with integrated activities that are expected of a person, and that those expectations will differ between culture, then a classification of all, or an overlapping common set, of integrated activities should be feasible.

But if our hypothesis is that a universal classification and assessment of disability is a possibility, how do we identify commonalities without losing sight of the cultural and linguistic differences and integrate these into the development of these instruments?

The cross-cultural applicability research (CAR) on disability that will be reported in this volume was a response to this challenge. Is it possible to identify and measure those concepts that form the conceptual core of disability phenomena without losing sight of the differences that occur across cultures? What can we learn from the similarities even as we observe the differences?

An overview of cross-cultural applicability research (CAR)

Although the next two chapters will lay out in detail the rationales and methodologies of the CAR research, a few preliminary remarks about this complex, international research might be helpfully made at this point.

As mentioned, the research initiative described here was the second phase of the WHO-NIH joint project, principally aimed at developing disability assessment instruments applicable in different cultures, for comparative statistical purposes. Ultimately, this information will be of help in the organization of health services around the world. In order to achieve this, it was felt that two important issues needed to be addressed:

1. The cultural relativity of the disability construct; and
2. The psychometric requirements for the development of cross-cultural instruments.

To ensure cross-cultural comparisons, it was agreed that a cultural equivalence should be sought for the disability construct, as well as the classifications. This equivalence can be expressed as a function of three specific equivalences and research questions:

- *Functional equivalence*: can one define similar domains of activities in different societies and cultures that serve the same function in different cultures?
- *Conceptual equivalence*: is there an equal understanding of the meaning of disability concepts across cultures?
- *Metric equivalence*: do the measured constructs exhibit essentially the same measurement characteristics in different cultures?

To achieve cultural consistency in the assessment of disability, the process of assessment itself must be similarly understood in different settings. The assessment terms, and their definitions, need to be examined cross-culturally. Moreover, the research should examine the comparable anchor points of disability (levels of distress or noticeable dysfunctionality, which may

differ between cultures) and thresholds of disability (when a level of disability that allows a person to take a day off work, or the socially recognized criteria for early retirement or the administrative judgement that someone is unable to work). It was expected that the identification of a common basis for such assessment domains, scales and probing styles would assist the construction of cross-culturally valid instruments.

The CAR study was principally aimed at identifying the cultural consistency of the disability construct found in ICIDH-2, in the context of ADM disorders. To do this, it was necessary to generate and test an item pool of disability terms as well as identify the anchor points or thresholds for the manifestation of disability. The study also sought to identify appropriate assessment domains and facets, and eventually appropriate questions for instrument development, and to begin the task of assessing their applicability, potential use and reliability.

The qualitative methods employed in the CAR study were chosen to provide the investigators with information relevant to the evaluation of the domains of disability that could be the focus of assessment in a suitable instrument. Each domain (as well as sub-domains, and individual facets or items) needed to be evaluated for cultural applicability. Five specific aspects of cultural applicability were identified as salient:

1. General applicability: whether a domain, sub-domain or item corresponded to identical or similar concepts in the local culture;
2. Applicability for translation: whether each domain, sub-domain or item translated without distortion or loss of meaning into the language (or whether a new English term was needed);
3. Applicability for key groups: whether all domains, sub-domains and items were applicable across age, gender, socioeconomic status, occupation, professional group or service agency;
4. Current needs and practices: whether the domains, sub-domains and items fitted the needs and practices of institutions of the culture in order to assess disability; and
5. Social security applications: whether the domains, sub-domains and items were appropriate for local legal and social security agencies and related services.

The CAR study also focused on the general evaluation of the assessment items, that is the clarity of each item and its definition, the utility of each item, and its placement in the classification. The completeness of the item pool was also considered in order to identify missing aspects of disability assessment.

In order to ascertain the applicability of the assessment items across cultures, the CAR study looked into what disability categories and terminologies were in use in the culture in clinical services, social security, primary care services, and rehabilitation and occupational therapy.

In the area of global policy for persons with disabilities, the CAR study sought information on how the local culture affected the process of disablement in the areas of care service utilization and coverage, social security and compensation and, more generally, on the degree and extent of stigmatization of ADM disorders.

The qualitative methods used in the CAR study consisted of,

1. A detailed description of the disablement process in each culture or cultural setting;
2. Linguistic analysis of each assessment item (domain, sub-domain and specific item);
3. Concept mapping for each assessment item;
4. Key informant interviews;
5. Pile sorting of assessment items;
6. Focus groups.

The procedure used for each of the methods is described separately in the next chapter. It must be noted here that though the thrust of the CAR study was qualitative and an attempt was made to build a classification and assessment from the "bottom up," several variations of qualitative techniques allowed for quantitative comparisons. The concept mapping technique, which used several dimensions in the mapping, allowed for the identification of those dimensions that are central across cultures in determining the salience of items. The pile sort methodology provided a quantitative clustering and comparison across different settings and respondent groups. Embedded in the key informant interviews were self-report pre-coded questions that were scored on ordinal scales to detect stigma and discrimination as well as the existence of environmental barriers and facilitators. These approaches proved to be useful complements to the more in-depth qualitative interview methods described later in the monograph.

The sites for the CAR study were chosen to reflect a diversity of culture, language, physical environment and mode of health service provision. Consideration was given to whether a CAR centre had experience in the assessment and classification of ADM disorders and disabilities, as well as familiarity with qualitative and quantitative research methods. Also crucial was a

willingness to participate and a readiness to take part in international research and the capability to carry out the basic requirements of the protocol.

The objective of the CAR study was to gather information about a culture's understanding of the disablement process and the societal response to it. It was important, therefore, to identify the best possible informants within each culture. Prototypical representation was sought, rather than probabilistic or random sampling. People were selected as spokespersons for their cultures. Doing so not only provided cross-cultural insights into the social representation of the disablement process, but also gave face validity to the constructs making them more useful in the development of assessment instruments.

In what follows, we hope to show the value of the CAR study in the validation of a true international common language of disability, and the development of assessment tools that are both culturally appropriate and scientifically valid and reliable. We also hope to demonstrate the possibility of resolving the apparent contradiction between ensuring cultural applicability of disability assessment items and the universality of the disability construct and the classifications that follow from it. The focus of the study has been to search for deeper similarities rather than to emphasize differences.