

Chapter 21

Summary and Conclusions

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The effectiveness of the CAR methodological suite

The CAR suite of methods, by combining the strengths of both qualitative and quantitative research, provided excellent and extensive information to guide the ICIDH-2 revision. At the same time, these methods allow the accommodation of a substantial degree of cross-cultural variation that would otherwise hinder the development of a universal language. The methods were chosen to complement each other, and this combination met the need for triangulation, that is, the need to substantiate the findings by means of multiple data collection procedures. This combination of methods also helped to satisfy the statistical requirements of reliability and validity. In addition, each of the methods on its own produced significant results.

Linguistic analysis

The concept mapping and linguistic evaluation exercises were intended to examine the effectiveness of the conceptual transfer that elements of a classification must undergo in order to meet the minimum requirements for a truly universal language. In the past, the standard procedure for making a document cross-culturally applicable has been to run it through a translation and back-translation process, in order to identify any problems with lan-

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guage. However, this process has been shown to be only partially effective. As a result, the CAR study incorporated an expanded translation and linguistic analysis protocol.

First, the translation was accompanied by a concept mapping and linguistic problem reporting process that not only identified problems in translating words from English into other languages, but showed problems of ambiguity in the original language as well. This allowed the simultaneous improvement of the classification in the original language and in the target language. Second, the linguistic analysis protocol used an innovative approach in providing, for a selected list of the terms, sentences in English that illustrated the nuances and connotations of the terms. This enabled translators to capture the intended use of the terms without necessarily being restricted by the back translation process.

The linguistic protocol identified problems at the level of terms in the classification (which were then appropriately modified or clarified), at the level of concepts (leading to the modification of definitions and structural relationships), and at the theoretical level (suggesting improvements in the rationale and structure of the classification as a whole). For example, most sites reported problems with translation of the term "disablement" to encompass the negative aspects of the three dimensions of functioning (namely, impairments, activity limitations and participation restrictions). As a result, the term was replaced with a more common term – "disability" – as the new umbrella term.

It is gratifying to note that fewer than 10% of the elements were considered problematic. It is, however, quite clear that in people's minds disability is a unitary experience often difficult to separate into impairments, activity limitations and participation restrictions. Although items belonging to the last category are clearly distinguished from the other two, they were found to present the greatest difficulty in cross-cultural application.

Pile sorting

The stability of items and their conceptual boundaries were explored by means of the pile sorting exercise. This is a method used in cognitive anthropology, where it is designed to explore the relationship of items in a cultural domain, in this case, the relationships of items in a classification of disabilities.

The CAR study was able to collect samples of the ways in which individuals from many different cultures would create a natural or indigenous classification out of the two-digit items in the ICIDH-2 classification, without any necessary reference to the existing classification. These samples

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showed how the items would be clustered into groups that were meaningful within a particular culture. We were then able to provide three types of information for the revision process. First, it was clear that there was a core set of concepts (items and definitions) that were very stable across cultures. These items form the conceptual and practical core of the ICIDH-2 classification and their stability provides strong evidence that the structure of the classification is not only theoretically viable, but is empirically validated across multiple languages and cultures. Second, the process allowed each language and culture group potentially to identify the items and concepts that differed from the global core in their language and culture. This information is valuable for local translation, and construction of a defensible classification that is true to the original. Third, the process identified problematic items that needed to be addressed in the original classification, since there were far too many cross-cultural differences in the ways they were placed in the classification in multiple languages and cultures.

There are several examples of changes made to the classification as a result of the findings from the pile sorting, especially when these results were combined with the linguistic analysis and the concept mapping results. For example, terms such as "executive function" as a technical term were not understood, and the term "environment" raised difficulties in several languages.

Concept mapping

The concept mapping process was intended as a structured and quantitative supplement to focus groups as a method for exploring items within the classification across several dimensions. It provided highly specific data at the item and definition level of the classification. However, the study design was too ambitious and so resulted in a heavy burden on respondents. The information on individual items was valuable, but the number of questions asked, the repetitive nature of the exercise, and the number of individuals who indicated that they had trouble completing the exercise reduced the usefulness of the data somewhat. The problem items identified in this process were very similar to those identified by the pile sort and the linguistic analysis. Concept mapping allowed the exact nature of the problem to be explored (whether, for example, it was an issue of cultural taboo or insensitivity to age, gender, and so on). However, there should have been fewer than 10 questions asked for the 90 items, and the structure of the questions should have been improved. This was taken into account in the subsequent ICIDH-2 field trials, with much improved results.

Despite these problems, the information was extremely valuable for the revision process and to help the centres learn about the cross-cultural issues in the classification. Some of the terms that were found to be culturally sensitive at a number of sites were not used as key terms in the classification and others that were unclear were defined more explicitly to increase their ability to be understood.

Key informant interviews

The key informant interview procedure is standard, and has been used many times for this type of purpose (Trotter & Schensul 1998; Bernard 1998). Traditionally, key informant interviews have relied on qualitative interpretations of verbatim records of such interview material. In this case it included qualitative open-ended questions supplemented by quantitative exercises that have proven very valuable. These interviews give us important evidence about the general level of social support for disabled persons, the governmental and nongovernmental responsibilities for assistance, and the relative rankings of disabilities in terms of their social impact within the culture. The results of this study were especially valuable because of the wide cross-section of key informants included. All of this information was used for expanding and revising the evolving disability paradigm embedded in ICIDH-2. The information was also useful in developing the conceptual framework for the ICIDH-2 based disability assessment instrument (WHODAS-II), and will be helpful in the future to further develop the notion of burden of disease and use of disability-adjusted life years (DALYs) as a summary health measure (Murray & Lopez 1996).

Focus groups

The focus groups provided some valuable information for the CAR study, especially in the description of cultural variability of stigma, information about assistance models, and both familial and societal attitudes and responses to disabling conditions. Also explored was the issue of the lack of parity in the treatment, both by governments and by society at large, of people with physical disabilities as compared with those with mental disabilities. The method was thus valuable for the overall revision process. Moreover, all centres commented that the information produced by this method was very valuable. It was almost universally remarked that focus groups provided the centre researchers with important information about disabilities in their cultures

and that they had not been exposed to at this level of detailed information in the past. The information helped the centres to acquire different viewpoints about disabilities, as well as a better understanding of the social processes that surround disabling conditions.

In conclusion, all of these qualitative methods, separately and in combination, did the job they were designed to do. In many instances, too, substantial new information about disabilities was acquired by the centres that participated in the study. We certainly recommend that the methods be used together, in a coordinated manner, for future cross-cultural applicability studies.

Principal results

The meaning of disability

One of the important findings of the CAR study is the confirmation that disability has multiple meanings that must be accommodated in a classification, and that no one meaning holds the key to the future of disability policy. The study incorporated processes (both data collection and revision strategies) that included multiple simultaneous viewpoints from disability researchers, policy-makers, persons with disabilities, care-givers, and the general public. This created a process that aimed at achieving the right balance of legitimate viewpoints, which, though difficult to carry out, greatly strengthened the outcome.

In spite of the rich diversity of viewpoints expressed and the explicit recognition of differences in the way disability issues are construed the world over, it was also gratifying to note the commonalities across the centres. Uniformly, respondents pointed out the stigma associated with disability, the lack of parity between mental health, alcohol and substance use and physical health conditions, and the role of physical and attitudinal barriers in the construction of disability. That disability needs to be understood as a social as well as a medical construct was amply highlighted. It was also clear that across the world disability is understood as an experience that affects the body and mind, the person as a whole and societal interaction in general. This conception of disability is uniform across centres, although respondents were not always sure how to deal with "invisible" disabilities (such as some forms of cognitive impairments) or those for which in some way the person is held responsible.

The role of social attitudes in the disablement process

The CAR data lead to a number of insights into the role of social attitudes towards disabilities. In each society, social attitudes are imbedded in the accommodation and compensation systems that were described by the CAR centres. Attitudes differed according to cultural assumptions about the responsibility of persons with disabilities for both the cause and the accommodation of the disability.

In some cases, there are competing or conflicting cultural views about causation. In some cultures, a person is treated more sympathetically, and provided with more public support for accommodation, when the disability is the result of a birth defect or an accident than if there are other causes. In these cultures, the condition is seen as not being the fault of the individual or his or her family, and therefore deserving social compensation or accommodation. In a very few cultures, both physical and mental health problems are seen in this light, and are treated with something close to parity. However, the opposite view prevails in a large number of cultures. Both accidents of birth and accidental physical injury are seen as linked to prior or current social and spiritual transgressions on the part of either the individual or the individual's family. In these cultures, the family is seen as being at fault and the societal values do not support governmental or societal accommodation of the disability. This complicates the stance of etiological neutrality in ICIDH-2, and places these societies in conflict with cultural norms that are aggressively attempting to destigmatize disabilities, and to achieve parity between mental and physical health conditions. This is a key cultural diversity issue raised by the CAR study and one that will need significant attention in the future.

Etiological neutrality

The model of disability in ICIDH-2 classifies dimensions of disability independently of their causal or etiological background. This means, in part, that no assumption is made within the classification of the likely or necessary causes of any activity limitation or participation restriction. Etiological neutrality, as this assumption is called, ensures that ICIDH-2 can be used by many and diverse users without committing them to any particular theory about the causes of disability. The CAR study results clearly support the need for etiological neutrality in the overall classification, while at the same time indicating that the lack of etiological neutrality in the cultural views of disabilities around the world has significant social impacts.

Parity

There is clear evidence that physical disabilities are perceived in public life as being less deserving of public support than mental health conditions, and the concept of parity between the two is not widely understood.

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Parity

There are two important findings in the CAR data relating to parity. First, it is clear that mental health conditions, and the social behaviour that accompanies those conditions, is far more threatening to society at large than most physical health conditions. This threat is caused by a deviation from expected social interactions, and an inability to predict social responses at work, in public, and to a lesser extent at home. The effect of this threat is expressed in lack of social support for alcohol- and drug-related disabilities (since these are perceived to be self-inflicted), and for the lack of parity in programmes for disabilities associated with mental health conditions compared with common physical impairments (for example, blindness, deafness, or paraplegia). While ICIDH-2 is designed to accommodate the activity limitations produced by disabilities associated with either mental or physical health conditions, most societies are not yet ready to relinquish differential treatment of the consequences of the two different conditions. This disparity must be taken into account when using ICIDH-2 internationally.

A second finding is that there are a number of societies in which the issue of parity between physical and mental impairments is effectively a moot point at this time. These are cultures in which all forms of disability are so highly stigmatized that it is irrelevant to try to make distinctions between the causal factors. In these cases, the social stigma and consequences of disabilities become of prime importance for addressing the needs of disabled persons in the society, and the lack of parity then becomes a secondary factor.

Ranking the severity of disabilities

Concerns are often raised about whether people's perceptions of the severity of a disabling condition in comparison to another are uniform across settings and populations. When the key informants in this study were asked to conduct ratings on the disabling effects of different health conditions, it was understood that the diversity of informants, sites, languages, and cultures would allow us to develop a sense of whether these conditions are rated similarly or differently across cultures and informant groups.

Since the key informants were also asked about social disapproval and stigma, it was possible to consider the extent to which the ranking of severity of a disabling condition was a function of the stigma or disapproval in society. The study results showed consistently that higher stigma was associated with higher disability ratings. However, stigma was not the major determinant of the ranking.

In fact, it is worthy of note that although there is some variation in ranking by key informants of the disabling effect of health conditions, such rankings are overall relatively stable across countries and informant groups. In the eyes of the respondents the relative burden of different health conditions in terms of disabilities was fairly similar across the world. The results also indicate, however, that there are systematic cultural differences, as well as differences between informant groups. These differences are large enough to need to be further explored in a systematic way, with a triangulation of in-depth qualitative and quantitative methods.

The actual burden of disability is affected by the physical and social environment that creates the context in which the individual lives. For example, the burden of disability for persons with paraplegia depends on the available assistive devices (wheelchairs, adapted cars, adapted workplaces) and on the social support available. This would lead one to believe that the weight that people ascribe to different conditions will vary widely across settings. Clearly, there are differences between countries in terms of services and attitudes, and these differences should be reflected in different disability weights attached to certain health conditions. This may in fact happen when valuation of health states includes the assessment of several other parameters that influence the health experience.

The most variable condition in our sample is HIV infection, which was ranked from the most disabling of all health conditions presented in Egypt and Tunisia to the third least disabling condition in Luxembourg. The differences expressed by expert groups are less dramatic but still important. Doubtless, the differential availability of expensive treatment or the varying degree of stigma may contribute to these quite different judgements.

In general, physical conditions are ranked more uniformly and universally compared to mental conditions across countries. Physical conditions such as quadriplegia and vitiligo are almost always considered the most and the least disabling respectively, but mental health conditions often fall in the intermediate range and show the most variation across centres. This is not true, though, when comparisons are made across persons who either have the health condition themselves or care for someone with such a condition. The lived experience with a disabling health condition seems to override other determinants of the value attached to disability. In other words, though aggregated responses across countries seem to show a common pattern, individual health experiences influence the judgements of severity of health states rather differently. These results have important consequences for the assignment of disability weights for the calculation of burden of disease using the DALYs measure (see Üstün et al. 1999).

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Social disapproval and stigma

The extensive data obtained from the key informants in this study reveal some clear messages. Drug- and alcohol-related conditions are always more stigmatized than mental disorders, and these are in turn more stigmatized than physical disorders. Disabilities associated with these conditions also meet with social disapproval in the same order. Predictably, while respondents seem to consider conditions for which the individual is somehow seen as responsible (such as drug and alcohol disorders) as the most stigmatizing, they are willing to consider environmental factors that may have brought on the disability to be mitigating. Issues raised by genetic causes of disability, and whether or not they are present at birth, are complex and viewed differently in societies where cultural beliefs such as the doctrine of karma, prevail. There is no doubt, in general, that social attitudes and moral values are key factors in determining how people across the world view disabilities.

Cultural diversity versus universality in ICDH-2

Qualitative research provides us with an understanding of the meaning that people attach to different concepts. It gives us insights into how these concepts "live" for the subjects of the research inquiry. To ensure that these insights are well grounded, researchers must allow concepts and theory to emerge from the data in order to develop hypotheses that can then be systematically tested (Strauss & Corbin 1994). Qualitative methods are best suited to the examination of complex situations where the exact nature of the relationships of several variables is not clearly understood. These methods allow for the generation of data for modelling the quantitative relationships between variables. The emergent results must be credible, transferable, confirmable and dependable (Hill 1991; Bernard 1998; Schensul & Le Compte 1999). The study findings should make evident sense.

The qualitative research used in the CAR study enabled us to recognize the differences as well as the commonalities across cultures in the perception and understanding of the disability construct. Cross-cultural research recognizes the "difference analysis" and the "search for similarities" as independent, and equally valuable, approaches that have different conceptual bases and methodological implications. Careful observation of a small subset of behaviours included under a hypothetical construct can capture the essential aspects of the construct, despite the wide variety of differences in manifest behaviour. This, then, is the rationale for finding a common set of variables that can form the basis for classification and measurement.

The underlying research agenda should attempt to find "equivalents" across cultures, while being aware of the factors that are responsible for the "bias" of differences. Results obtained in different cultures can then be used to evaluate the intercultural differences or else to assess the equivalent results across the different cultures.

Our results show that there is a considerable variation across our centres in terms of the language available to express disability constructs, the services for persons with disability, the attitudes towards and stigma surrounding disability, the acceptability in society of persons with disability, and the comparability of disability associated with physical and alcohol, drug and mental disorders.

In spite of these differences, however, some clear common themes have emerged. Disability is universally recognized as an aspect of the human health experience. Across cultures, the phenomena of disability are viewed as occurring at the level of the body functions or structures, at the level of the person in carrying out day-to-day activities, and as a direct result of barriers and hindrances that they encounter in their environment. Across the world, disabilities are stigmatized, though the extent and quality of this stigma varies and there is a clear bifurcation in attitudes about and services for people with physical health problems as opposed to those with alcohol, drug and mental disorders.

At the level of detail, the study makes it clear that, though living with a disability is a different experience across cultures, nonetheless there is agreement about which activities are essential to human functioning at the three levels. Across the centres, respondents tended to group together sets of activities that they felt were building blocks of human functioning. These range from interacting with one's environment, taking care of oneself, moving around and relating to others, to working and performing household activities and participating in a wide range of other social activities. Once again, though the manner of accomplishment of each of these vary, respondents uniformly recognize the importance of core human activities, from the relatively simple tasks of dressing and feeding oneself to more complex behaviours such as engaging in political activity or community events.

In the Introduction we described a fundamental dilemma for the revision of ICIDH-2, namely that, as an international classification providing a common language of disability, ICIDH-2 must offer a universal conceptual framework for disability across languages and cultures. Yet the experience of disability is, in some sense, unique to each individual, and anthropological and ethnographic research, including of course our own, suggests that this experience is in large part constructed from the cultural, linguistic and social environment in which each person lives. How can we create a universal lan-

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guage in the face of apparent cultural diversity? What has the CAR study to say about this dilemma?

If we recall the distinction earlier made between "weak" and "radical" relativism, the data presented in this volume make it abundantly clear that the radical position of complete and non-remediable incommensurability of the disability concept across cultures is radically mistaken. To be sure, the work reported here was preliminary, and can and should be extended to more countries and cultures, and involve more detailed features of ICIDH-2, both as a construct of disability and as a classification. Nonetheless, the results reported here make it apparent that the radical position is likely to be false or at least unjustifiable on the evidence.

It is understandable for researchers in the field to be impressed by the differences in their respondents' understanding of disability. They are, after all, highly attentive to differences. Similarities are often more difficult to detect. And fundamental similarities at the level of the construct itself – for example, that disability is a tripartite concept with clear differences between body, person and social levels – are even more difficult to identify. The CAR methodologies are, for reasons already explained, well suited to allow us to sift through the differences to identify the underlying similarities, without thereby falling into the opposite trap of discounting the differences as irrelevant or trivial.

For indeed the differences in cultural perceptions of disability are neither irrelevant nor trivial. The data presented in the previous two chapters make it clear that there are considerable cultural variations in perceptions of relative stigma, valuation, parity and underlying societal evaluation that are crucial to policy development. Refining these differences, and finding other, as yet undiscovered similarities, is work for the future. But we are in a position now to say with authority that the empirical evidence supports the possibility of a transcultural, common understanding of disability and, as well, an international common language of functioning and disability categories that can be used from country to country without surreptitiously imposing one cultural understanding on the rest of the world.

The CAR results, preliminary though they are, also indicate the importance of using state-of-the-art qualitative and quantitative research methodologies to acquire the empirical data needed to substantiate the many presuppositions about disability that one finds in the literature. In a recent note, Nora Groce claims that a cross-cultural perspective on disability shows that the disadvantages associated with disability are caused by the social environment (Groce 1999). Her claim may well be true. Unfortunately, we do not have the worldwide information to be sure *if* it is true, and more importantly, *how* in specific terms it is true. Without the data and the specifics, the

claim takes on the appearance of a political slogan rather than an evidence-based claim.

What is ironic, though, is that often the scholars and researchers who firmly believe, to quote Groce again, that "the lives of individuals with disability are limited not so much by their specific type of disability as by the social interpretation of that disability" are radical relativists who refuse to grant the possibility of a universal disability construct, or the usefulness of an international classification such as ICDH-2. This stance is, on the face of it, self-defeating, since the claim of environmental causation will remain a political slogan rather than a confirmed scientific hypothesis unless the measurement work can be done to demonstrate quantitatively how the environment causes the disadvantages of disability, and how we can change the environment to eliminate or alleviate these disadvantages.

The research challenge posed by the ICDH-2 and related assessment instruments

Though the CAR study has demonstrated the feasibility of undertaking the mammoth exercise of developing a common language of disability within the wide diversity that exists cross-culturally, the task is far from complete. Certainly the results of the study indicate that technical language must be converted into simpler terminology and care will have to be taken to explain the theoretical and philosophical underpinnings to potential users. The challenge of making the classification useful for day-to-day applications, ranging from clinical uses to policy development, is being addressed by WHO through its strategies for implementing ICDH-2 as well as associated assessment tools such as WHODAS II and the ICDH-2 checklist.

Building a common language of disability that is not only cross-culturally valid but also lives up to its claim of being etiologically neutral in order to create parity across specific health conditions is, of course, a tall order. Ongoing field studies of ICDH-2 and WHODAS II should provide empirical data on how these tools fulfil these goals. The need to establish workable thresholds for disability will continue to be addressed, as thresholds form the basis for many vital resource allocation decisions. Multidimensional assessment of disability, which distils several factors into a single metric, is also a challenge. The need to account for subjective perceptions of health states as well as individual and social valuations of them makes the situation even more complex and the task even more daunting.

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The road ahead

In the future it is hoped that a true synthesis of the biological, psychological and social influences in the disability experience can be constructed and scientifically validated. This synthesis must be based on systematically collected evidence, not political rhetoric. ICDH-2 offers a cross-cultural and international framework for collecting evidence that will assist researchers, policy-makers and advocates to understand more fully the impact of health conditions. The success of ICDH-2 as the international common language for disability will be a fitting tribute to the cross-cultural applicability research described in this volume.