The Environment in the International Classification of Functioning, Disability and Health
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Background The World Health Organization has adopted two classifications relating to disability, one was published in 1980 and the more recent one in 2001. Although the international classification of functioning, disability and health (ICF) was drafted as a revision of the international classification of impairments, disabilities and handicaps (ICIDH), the ICF is based on major changes when compared with the ICIDH. One of them has to do with the environment.

Method Quotations from the classification manuals and related articles are presented in order to make clear the scope of the environment in the ICF.

Results The ICF has a universal application. The gap between capacity and performance reflects the barriers created by the environment.

Conclusions In the ICF, universalism and barriers have specific meanings, reflecting specific policy choices.

Keywords: causation; environment; international classification of functioning, disability and health; international classification of impairments, disabilities and handicaps; universalism.

The International Classification of Impairments, Disabilities and Handicaps

A short overview of the international classification of impairments, disabilities and handicaps (ICIDH) is useful in order to understand the more recent international classification of functioning, disability and health (ICF), which was drafted as a revision of the older one. The manual of the new classification refers to the ICIDH and explains why major changes were decided. When the ICIDH was adopted, it was the first time that an international institution provided a definition of disablement and a classification founded on this definition. They were in use for approximately 20 years (1980–2001). The ICIDH stated that disablement was a compound of different notions separate but related to each other. Several other definitions of disablement were published in the literature during that period of time, yet ICIDH was one among very few that were used to build a classification.

The General Assembly of the World Health Organisation (1980) (WHO) adopted the ICIDH in 1976. It was published in 1980 ‘for trial purposes’. The subtitle, as printed on the cover of the manual is: ‘a manual of classification relating to the consequences of disease’. This relation to disease is stressed at the beginning of the introduction: the ICIDH is ‘concerned with dimensions of health-related experience complementary to those embraced by the concept of disease’ (p. 7). The ICIDH was meant to classify information not included in the international classification of disease, which ‘fails to reflect the full range of problems that lead people to make contact with a health care system’ (p. 10). Indeed, the very first sentences of the introduction states that one purpose of the ICIDH is to contribute to the improvement of health care systems: ‘the ability-capability gap, the discrepancy between what health care systems can do and what they might do, constitutes one of the greatest challenges for those concerned with health care and welfare. The hope is widely shared that improvements in the availability of relevant information could make an important contribution to the development of policies more appropriate to the solution of these problems’ (p. 7).
In order to help gather relevant information, the ICIDH is built on a conceptual framework. According to this framework, the consequences of disease can be described on three planes of health experience. The first one has to do with parts of the body or of the person: organs and functions. On this plane, problems are called impairments, according to the following definition: ‘in the context of health experience, an impairment is any loss or abnormality of psychological, physiological or anatomical structure or function’. The second plane of experience ‘is concerned with compound or integrated activities expected of the person or of the body as a whole, such as represented by tasks, skills and behaviours’ (p. 28). Any difficulty arising in this domain is called a disability: ‘in the context of health experience, a disability is any restriction or lack (resulting from an impairment) of ability to perform an activity in the manner or within the range considered normal for a human being’. The third plane ‘is a social phenomenon, representing the social and environmental consequences for the individual, stemming from the presence of impairments or disabilities’ (p. 29). These consequences are called the social disadvantage, or the handicap: ‘in the context of health experience, a handicap is a disadvantage for a given individual, resulting from an impairment or a disability that limits or prevents the fulfilment of a role that is normal (depending on age, sex, and social and cultural factors) for that individual’. A table shows a linear progression from disease to impairment, and then to disability and handicap. Although the introduction explains at length that in fact things are not so simple, this linear progression was much criticized.

The ICIDH manual explains that this framework is of particular interest for chronic conditions. Indeed, for acute ones, the diagnosis contains most of the necessary information: after a not very long span of time, patients recover or unfortunately, they die. The situation is totally different in chronic conditions, where the diagnosis remains the same as time goes by, while the patient experiences varying states. Moreover, different patients having received the same diagnosis may in fact experience different situations.

The relations between acute and chronic conditions were under close scientific scrutiny at the time when the ICIDH was drafted. One major contribution was written by Omran (1971, 1974) and dealt with the epidemiological transition. According to Omran: ‘during the transition, a long-term shift occurs in mortality and disease patterns whereby pandemics of infection are gradually displaced by degenerative and man-made diseases as the chief form of morbidity and primary cause of death’ (p. 516). Moreover, Omran’s view highlights the role of socio-economic situations in the changing relations between acute and chronic conditions: ‘the shifts in health and disease patterns that characterize the epidemiological transition are closely associated with the demographic and socio-economic transition that constitute the modernization complex’ (p. 527). Professor Philip Wood, who drafted the ICIDH as consultant to the WHO, was interested in this aspect of the problem.

A critical appraisal of the ICIDH may underline three strengths and three weaknesses. The positive points are as follows: the ICIDH provided a clear conceptual framework in order to describe the experience of persons with chronic conditions. This framework was meant as a dynamic approach to disablement, including the relation between different factors and changes with time. The ICIDH was clearly designed with a public health approach. On the contrary, the negative points were no small ones. The classification was not very well designed and was hardly used as such. The WHO never spent a single dollar on the follow-up of the ICIDH, nor did it organize any meeting of users, nor prepare any update. Different users had different understandings of what was in the classification and of how it should be used. Finally, when the time for revision came, a majority was against the ICIDH. During the entire revision process, the task forces were working towards an ICIDH-2. When the final version was completed, it needed a new name: it was the ICF.

The International Classification of Functioning, Disability and Health

A largescale international revision process took place from 1993 to 2001. The new classification was adopted by the General Assembly of World Health Organisation 2001 (Resolution WHA54.21). On 12 pages of the manual, people and organizations involved are listed (pp.254–265). The French Collaborating Centre of WHO for ‘research and training in mental health’ was involved in the process within the International Task Force on ‘mental health and addictive, behavioural, cognitive and developmental aspects’ of ICIDH (Chair: Dr Cille Kennedy). The French Collaborating Centre was involved in the work and in the debates that took place during that period (Chapireau & Colvez 1998).

The International Classification of Functioning, Disability and Health is a book of 300 pages. It is therefore likely that only specialists will study it thoroughly. A summarized presentation will be useful before discussing the environment in the ICF.
Principles of the ICF

The ICF is based upon principles that differ from those of the ICIDH. First, while the ICIDH provided a classification of what may be a problem, the ICF is a classification of neutral components of health. The ‘ICF’ has moved away from being a ‘‘consequences of disease’’ classification to become a ‘‘components of health’ classification’’ (p. 4). In other words, the ‘ICF’ encompasses all aspects of human health and some health-relevant components of well being and describes them in terms of ‘‘health domains’’ and ‘‘health-related domains’’ (p. 7). When using the classification for coding, one has to specify with a qualifier whether there is or there is not a problem. Another important feature of the ICF is universalism: ‘‘there is a widely held misunderstanding that ICF is only about people with disabilities; in fact it is about ‘‘all people’’. The health and health-related states associated with all health conditions can be described using the ICF. ICF has a universal application’ (p. 7).

Structure of the ICF

The ICF is a classification of human functioning: ‘‘functioning is an umbrella term encompassing all body functions, activities and participation; similarly, disability serves as an umbrella term for impairments, activity limitations or participation restrictions’’ (p. 3). The structure of the classification is as follows: ‘‘the ICF has two parts, each with two components: part 1. Functioning and disability: (a) body functions and structures, and (b) activities and participation; part 2. Contextual factors: (c) environmental factors, and (d) personal factors. Each component can be expressed in both ‘‘positive’’ and ‘‘negative’’ terms. Each component consists of various domains and, within each domain, categories, which are units of classification. Health and health-related states of an individual can be recorded by selecting the appropriate category code or codes and the adding ‘‘qualifiers’’, which are numeric codes that specify the extent or the magnitude of the functioning or disability in that category, or the extent to which an environmental factor is a facilitator or barrier’’ (pp. 10–11). However, ‘‘personal factors are not classified in the ICF because of the large social and cultural variance associated with them’’ (p. 8).

Each health and health-related state is defined both in a positive and in a negative way. ‘‘In the context of health: body functions are the physiological functions of the body system (including psychological functions). Body structures are anatomical parts of the body such as organs, limbs and their components. Impairments are problems in body functions or structure as a significant deviation or loss. Activity is the execution of a task or action by an individual. Participation is involvement in a life situation. Activity limitations are difficulties an individual may have in executing activities. Participation restrictions are the problems an individual may experience in life situations. Environmental factors make up the physical, social and attitudinal environment in which people live and conduct their lives’’ (p. 10).

Models of functioning and disability in the ICF

Functioning and disability are approached in the ICF as processes, though the handbook claims that no specific model underlies this approach: ‘‘as a classification, ICF does not model the ‘‘process’’ of functioning and disability. However, it can be used to describe the process by providing the means to map the different constructs and domains. It provides a multiperspective approach to the classification of functioning and disability in an interactive and evolutionary process’’ (p. 18). Notwithstanding this statement, the manual points to the fact that ‘‘ICF is based on an integration of two opposing models’’ (p. 20). The first model is the medical one, which ‘‘views disability as a problem of the person, directly caused by disease, trauma or other health condition, which requires medical care provided in the form of individual treatment by professionals. Management of the disability is aimed at its cure or the individual’s adjustment and behaviour change. Medical care is viewed as the main issue, and at the political level the principal response is that of modifying or reforming health care policy’’ (p. 20). The second model is the social one, which ‘‘sees the issue mainly as a socially created problem, and basically as the matter of the full integration of individuals into society. Disability is not an attribute of an individual, but rather a complex collection of conditions, many of which are created by the social environment. Hence the management of the problem requires social action, and it is the collective responsibility of society at large to make the environmental modifications necessary for the full participation of people with disabilities in all areas of social life. The issue is therefore an attitudinal or ideological one requiring social change, which at the political level becomes a question of human rights. For this model disability is a political issue’’ (p. 20).

Coding the ICF

Body functions and structures each have a separate list of categories. It is important to note that activity and
participation, which have a different meaning and deal with different health experiences, are to be coded with the same set of categories. Each category can receive two qualifiers. The performance qualifier relates to what an individual does in his or her current environment; it describes ‘participation’ (p. 229). The capacity qualifier relates to an individual’s ability to execute a task or an action; it describes ‘activity’ (p. 229). For the environmental factors, ‘the qualifier indicates to which extent a factor is a facilitator or a barrier’ (p. 232).

Considering that ‘the activities and participation component is a neutral list of domains’, the ICF allows ‘four alternative options for structuring the relationship between activities and participation in terms of the domain list: (i) distinct set of activities domains and participation domains (no overlap), (ii) partial overlap between sets of activities and participation domains, (iii) detailed categories as activities and broad categories as participation, with or without overlap, and (iv) use of the same domains for both activities and participation with total overlap of domains’ (pp. 234–237). These four alternatives may in fact be five, as the third one is a choice of two. In any event, users of the ICF are allowed to change the structure of the classification according to their needs. This may be very useful but it may also create difficulties when trying to compare data not gathered according to the same rules.

Coding environmental factors is not so simple either. The first chapters of the ICF favour models that will involve reciprocal relations between a person and the environment. However, the coding guidelines do not allow a description of any such interaction. They only explain how to evaluate the influence of the environment on the person. A qualifier is used for this coding. It ‘indicates the extent to which a factor is a facilitator or a barrier’ (p. 232).

The manual also provides three coding conventions: Environmental factors may be coded alone, for every component (i.e. body functions, body structures, activities and participation), or for capacity and performance qualifiers for every item (pp. 225–226). However, ‘environmental factors must be considered for each component of functioning’ (p. 232).

The Environment in the ICF

The politics of universalism in the ICF

Much can be learnt about the ICF by reading the only article quoted in the manual (Bickenbach et al. 1999). This article was written by some of the leading experts who co-ordinated the revision of the ICIDH at the Geneva WHO headquarters. Being published in 1999, it still refers to the new classification as ICIDH-2. The abstract goes as follows: ‘a review and critique of models of disability is presented, tracing the development of frameworks and classificatory instruments (ICIDH) over the past 20 years. While the ‘social’ model is now universally accepted, it is argued that universalism as a model for theory development, research and advocacy serves disabled persons more effectively than a civil rights or ‘minority group’ approach. The development of the revised international classification (ICIDH-2) is discussed in this light’ (p. 1173).

One important point of this paper is about participation: ‘the salient feature of the condition of inequality among people with disabilities is that it typically consists of limitations on their freedom to participate in the full range of social roles and ways of living. Their freedom is not usually limited by expressed legal prohibitions – although that can happen – but by failures to provide the resources and opportunities needed to make participation feasible. In political theoretical jargon, this is called ‘positive freedom’, the freedom to achieve, through the provision of resources and opportunities, what it is that one wishes to do or become. The denial of positive freedom is characteristic of the disadvantages experienced by people with disabilities’ (p. 1181).

The authors go on to say that the best approach to positive freedom for people with disabilities is universalism, as was defined by the American sociologist I. Zola: ‘we need a political strategy which, as Zola framed it, “demystifies the specialness of disability”’ (p. 1182). Further on, the authors put it in their own words: ‘universalizing disablement policy begins by demystifying the “specialness” of disability. Rather than identifying special needs that require special attention (and special legislation, special agencies and special experts) we need to see that all people have needs that vary in roughly predictable ways, over the course of their life. Disablement policy is therefore not a policy for some minority group, it is a policy for all’ (p. 1182). Therefore, ‘our standards and codes should reflect a policy commitment to universal design’, and ‘the central strategic issue of a universalistic disability policy is to negotiate the range of human variation as the basis for universal design’ (p.1183). In the revised classification, ‘within the dimension of participation, universalism has been captured by setting the norm of full participation as the level of participation that could be experienced by an individual with no disablement’ (p. 1185).
Coding guidelines: a causal model of disablment

In this brief presentation of a long article, three main ideas have been stressed. First, people with disabilities experience a denial of positive freedom. Secondly, this denial comes from the environment. Thirdly, the most effective policy to restore positive freedom is universalism. How are these ideas translated in classification language?

Although they are quite technical, the coding guidelines are an essential part of the ICF, as ‘activities’ and ‘participation’ are to be described with only one list of categories and items. Without guidelines, the list is meaningless. The coding guidelines for ‘activities and participation’ express a causal model of disablment. This model, and no other, fits the coding guidelines, even though it is not described at the beginning of the manual. According to the model, the differences between ability and performance are caused by the environment. Therefore, changes in the environment are the way to maximize ‘participation’: the gap between capacity and performance reflects the difference between the current and uniform environment and thus provides a useful guide as to what can be done to the environment of the individual to improve performance (p. 230).

For coding purposes, the definition of ability excludes the influence of the environment. Ability is defined so to speak as ‘environment free’. The ICF calls this ‘the environmentally adjusted ability’: ‘to assess the full ability of the individual, one would need to have a “standardized” environment to neutralize the varying impact of different environments on the ability of the individual. This standardized environment may be: (i) an actual environment commonly used for capacity assessment in test settings; (ii) in cases where this is not possible, an assumed environment, which can be thought to have an uniform impact. This environment can be called “uniform” or “standard” environment. Thus, the capacity construct reflects the environmentally adjusted ability of the individual. This adjustment has to be the same in all countries in order to allow international comparisons’ (p. 229). The international classification manual does not state how users of all countries will implement this guideline. What is a standard environment for social and societal factors?

In some instances, the coding process is not so difficult, as for instance for the domains ‘basic learning’ or ‘walking and moving’, where tests are available. In other instances, the ICF brings a new challenge to users. It is not usual for coding guidelines to ask users to define ‘an assumed environment’. Users are not asked to assess something that is actually happening, but an ‘assumed’ reality, or in other words, what the real fact ‘can be thought’ to be under circumstances that in effect do not take place where and when the coding is undertaken. The manual says that it must be carried out, but it does not say how. Can we be sure that all users will perform that task in the same way, as for instance in the following domains ‘education’, ‘work and employment’ or ‘community life’? Implementing this guideline may be difficult for quite a few users. The four alternative options for the relationship between ‘activities’ and ‘participation’ do not make that matter easier. Possibly, they make it harder.

Disability and culture

One of the most difficult challenges for an international classification is that it should be acceptable all over the world, in most different settings. Research concerning this issue was organized by the leading experts who coordinated the revision of the ICIDH at Geneva WHO headquarters. It was called ‘the ICIDH-2 cross-cultural applicability research study’ (Üstün et al. 2001). Among the several references that are discussed in this book, one receives a special emphasis, the book edited by Ingstad & Whyte (1995). It is presented at length in the first chapter (pp. 13–16) and discussed again in the conclusion (p. 319). The two anthropologists write: ‘in many cultures, one cannot be “disabled” for the simple reason that “disability” as a recognized category does not exist’ (Ingstad & Whyte 1995, p. 7). On the contrary, the WHO experts conclude: ‘we are in a position to say with authority that the empirical evidence supports the possibility of a transcultural, common understanding of disability’ (Üstün et al. 2001, p.319). This point was important enough in Üstün’s view, for him to choose the same title as Ingstad and Whyte’s: Disability and Culture.

Here is what Üstün et al. say at first about the earlier book: ‘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 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’ (Üstün et al. 2001 p. 13). Ingstad and Whyte’s book is a collection of 12 anthropological studies. In their introduction they stress the fact that disability has to do with history and culture: ‘what is significant for our purposes at the moment is that the cultural conceptualization of humanity is variable; the anomalies that may be seen as inhuman differ greatly from one society to another, and they do not correspond directly to biomedical definitions of impairment’ (p. 11). When they speak of ‘conceptual problems of the most fundamental sort’, this is not to say that obstacles are overwhelming. It is to underscore ‘the basic problem of anthropology – how to interpret other people who are different’ (p. 278).

According to Ingstad and Whyte, ‘cultural relativism, the idea that phenomena must be understood within their cultural contexts, takes two forms. Within discussions of disability, a ‘weak relativist’ position is common. The point here is that the disadvantage posed by a disability depends on the capacities most prized or needed in a particular context. ‘Radical relativism’ seeks to reveal basic assumptions about what it is to be a person, and what kinds of identities and values exist in given social contexts; What is it people are trying to achieve? The strong version of relativism questions the terms of analysis and attempts to uncover the categories implicit in other worldviews. The concept of disability must not be taken for granted’ (Ingstad & Whyte 1995, pp. 6-7). Üstün et al. reply to this point is as follows: ‘if we recall the distinction made earlier 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’ (Üstün et al. 2001, p.319).

Here are Üstün et al. conclusions: ‘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. However, in spite of these differences 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 and structures, at the level of the person carrying out day-to-day activities, and as a direct result of barriers and hindrances that they encounter in their environment’ (p. 318).

The debate led by Üstün et al. on behalf of WHO may come as a surprise. After all, the two books are about two different topics. The purpose of WHOs was to validate an instrument in order to gather data to be used for the improvement of human conditions. Ingstad and Whyte’s were to understand what it means to be a person in different cultures. The two anthropologists certainly did not deny inequalities in health, nor the need to fight them. Possibly, they would challenge the very idea of a standard social environment, to be referred to for coding purposes. The question was not to put them.

Discussion and Conclusions

A critical appraisal of the ICF may, as for the ICIDH, underline three strengths and three weaknesses. The first strength is certainly the involvement of consumer organizations. They had an important role in the revision process, and still do in popularizing the ICF. The second one is universalism as a way to fight stigma and segregation. It is a powerful approach for mutual understanding between people who think they have no disability and people with disability. The third one is the purpose of changing the environment. Indeed it is an ever-thrilling ideal to fight for a better world to live in. The first weakness is that the ICF is much clearer about the physical environment than it is about the social and societal one. People with physical problems may derive more help from the ICF than others. The second weakness is that the ICF is difficult to operationalize for research. International comparability may be especially difficult to be precise about. Finally, not everybody will agree with the ICFs case against special legislation, as many countries have freely chosen to enforce such laws.

Environment is a very important component of the ICF. Environment is a separate list of items, to be coded together with the other components. Environment is also a central part of the causal model underlying the coding guidelines. An article and a book written by some of the leading experts who co-ordinated the revision of the ICIDH at the Geneva WHO headquarters show that this choice was deliberately made according to a strategy for a worldwide disability policy.
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