MEASURING THE CONSEQUENCES OF ILLNESS

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This article will concentrate on the International Classification of Impairments, Disabilities, and Handicaps (ICIDH) (1) as a means for measuring the impact of illness and its consequences. The ICIDH, for which I was largely responsible, was published in 1980. Looking back, it now feels as if this was the lighting of a very slow fuse. At first the ICIDH seemed to attract very little interest, but now there are encouraging indications that it is being used in different applications more and more widely. Slow uptake has been due to a variety of difficulties, some of which this article will examine. First, though, it is necessary to describe how the classification came into being.

Background

The earliest efforts seeking standardization for the recording and analysis of health-related information were confined to cause-of-death statistics. Even in 1856, however, Farr recognized that it was desirable "to extend the same system of nomenclature to diseases which, though not fatal, cause disability in the population" (2). The main thrust of international cooperation was the development of the International Classification of Diseases (ICD) (3), and in response to Farr's aspirations efforts were made to integrate mortality and morbidity into a single classification scheme— an aim that was finally realized only in the Sixth Revision of the ICD in 1948.

In the introduction to this Revision, in reviewing its application to causation, illness, and disability, it was noted that "an illness varies from a minor deviation from normal health, which does not interfere with the performance of regular duties, to the chronic case which calls for bedside or custodial care for an indefinite period". Here, 40 years ago, were the forerunners of definitions of health experience in terms similar to those used in exploration of relevant concepts in the introduction to the ICIDH. At the same time that morbidity was assimilated fully into the ICD, the need was also felt to extend the scheme with supplementary classifications of impairments, blindness, and deafness, which formed part of the Y code. This code was reproduced unaltered in the Seventh Revision of the ICD in 1955, but for the Eighth Revision (1965) the supplementary classification was restructured. On this occasion the Revision Conference noted that "the classification of impairments in categories Y40-88 was seen as a parallel code, collecting in one group a number of conditions scattered throughout the main code. It had been used by some countries in health surveys and the Conference, appreciating that such surveys were likely to increase, considered that it would be useful if such a classification appeared in the Manual of the ICD for optional use."

So by 1965 the principle of a separate but parallel code was accepted. Unfortunately in the process of editing the Eighth Revision for publication the optional classification of impairments was inadvertently omitted. The Revision Conference had certainly been prescient when it anticipated that surveys of impairments were likely to increase. Changes in the burden of disease were becoming more evident, with chronic and disabling conditions assuming a dominant position in many parts of the world. Omission of the Y code and consequent lack of a system to cope with data on these aspects thus emerged as a serious limitation, and there was increasing demand for an appropriate classification scheme to be developed in conjunction with the Ninth Revision of the ICD. Herein lay the immediate pedigree of the ICIDH, but certain aspects command further examination.

General considerations

After mortality the most burdensome consequence of illness is disablement. Implicit in the deliberations on health-related information was an assumption—that ICD-derived data, with their orientation towards the underlying causes of medical conditions or diseases, were not adequate for revealing the nature and scale of disablement in such a way as to illuminate policy development and promote improved services for those with disabilities. How justifiable was this assumption?

More than 10 years ago WHO estimated that in millions of 450 million people throughout the world were disabled, representing a prevalence ratio of 1 in 10. Fig. 1 shows the world burden of disability, based on WHO's estimates of the proportions accounted for by various of the major causes. As reported previously (4), I found it useful to inflict my own taxonomy on these data by dividing the whole into three groups—developmental, acute, and chronic. This is more helpful when considering the potential for prevention and control. Some 64% of the total is accounted for by developmental and acute problems, a large part of which could be prevented by the application of conventional public health insights. This conclusion is reinforced when it is recalled that one-third of those affected are children, and that four-fifths of the disabled live in developing countries. Much the biggest challenge on a global scale, therefore, is to find out why possible action is not taken, and standard ICD data serve this function fairly well.

The remainder of the burden is made up of chronic problems, which are less straightforward. The very designation "chronic" reflects that at present such
conditions cannot readily be arrested, and in the main they are not amenable to simple measures for primary control or prevention. This has two implications. Firstly, models of causality tend to be complex, invoking the interplay of multiple factors; it is because no one factor appears to be dominant in its effect that primary control measures are generally difficult to identify. Secondly, extended time scales mean that diagnosis, whilst still important, tends to be overshadowed by the existential problems of sustaining everyday life in an acceptable manner. In turn this means that the concept of disease accounts for an insufficient part of the variance in health status, so that ICD-derived data have only a limited power for revealing the nature and scope of the challenge. Herein lay the basis for concluding that ICD-derived data were not adequate to the problem. That said, and pending wider availability of ICIDH-based data, the value of rearranging ICD categories according to their disabling potential rather than the nature of the underlying morbid anatomical processes should not be neglected (5).

What gave further stimulus to development of a scheme for organizing data complementary to the approach adopted in the ICD has been broader alterations in society as a whole. It is in the domain of chronic illness, especially, which in this context includes conditions present at birth or resulting from accident or injury, that the nature of challenges confronting medical practitioners, scientific investigators, health service administrators and policy makers has been undergoing profound change. This has come about for five main reasons: (i) extension of health service provisions to increasing proportions of the population; (ii) escalating costs for such provisions; (iii) demographic shift towards older people; (iv) a concomitant alteration in the morbidity burden; and (v) emerging social and political awareness of disadvantage in society. Although it was largely in response to these that requests for something like the ICIDH began to be expressed, changes in the nature of illness experiences have themselves contributed to increased demand on health services, so that it is necessary to take account of problems of scale as well.

The implications of the emergence of chronic illness as a major problem have posed a number of challenges for medical practice; these were identified in an earlier paper (6). Such features made their own contribution to growing demand for appropriate care services. Uncertainty and ignorance about the nature and scope of the difficulties were evident, very much due to failure to study the outcomes of disease in such a detailed, scientific, and sophisticated manner as has been the case with diagnosis and etiology. However, the situation was compounded by lack of a conceptual basis for appreciating disease consequences, and by confusion in the terminology used in such contexts. This all served to cloud the messages transmitted to policy makers and politicians, at the same time offering justification for evasion of the problems posed by disablement because of unknown financial implications. Yet the need to take practical action was still pressing.

Scope of the ICIDH

A complex challenge therefore had to be recognized. Before proceeding further it is relevant to recapitulate what is axiomatic in taxonomy, that the criterion of utility is paramount (7). In other words, what matters is whether the exercise accomplishes its objectives and suits the purposes for which it was designed. Although what could be regarded as a classification's face validity has some practical rele-
vance, theoretical and ideological issues are of sec-
ondary importance. Here it is important to em-
phasize that the ICIDH, in its present form, does
not have any significant antecedent; it endeavoured to
provide an exhaustive listing of organ or system malfunction to comple-
ment the exhaustive enumeration of diseases in the
ICD. The disability code adopted an approach that
deliberately departed from conventional assessment
of activities of daily living (ADL). The latter tend to
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First it was necessary to establish basics, which
involved a return to the fundamental dimensions of
experience and an examination of relevant concepts
in a taxonomic or interrelational mode of
thought (9), the results of which are noted above. In
many ways the problems associated with disable-
ment present ambiguities that are encountered with
other human predicaments, such as old age, alcohol-
ism and loneliness (10), especially if the ICIDH at
tempts to help means of resolving some of the ambiguities, at least
in regard to disablement. A specific practical
problem is that service agencies responsible for respond-
ing to needs in this area are often administratively
separate and influenced by different historical tradi-
tions, and yet as far as chronic illness is concerned it is
recognized that a corresponding separation between the medical and social aspects of an
individual's needs. The particular relevance of the
conceptual distinctions noted above is that they
 correspond to the obligations of different sectors or
components of overall arrangements for care. Thus
impairments are primarily the concern of medical
services, and the disability and handicap, with
handicaps of social welfare provisions and broader
areas of social policy, such as those concerned with
education, employment, transport and housing.

It is on this plane that the ICIDH almost certainly
makes its most profound contribution, as a resource for
communications that are not entirely without
controversy, as will be discussed later. The ICIDH
helps to stimulate and illuminate thinking about the
nature of disablement, and it focuses attention on
issues such as indicators, quality of life and out-
come. At this level the ideas have been welcomed
by those involved with the education and training of
health and related professionals, enabling them to
preserve the coherence in thinking on what had
formerly been rather arbitrary and disjointed topics.
What is disappointing, though, is that the thinking
does not seem to have had any great penetration at
the level of policy makers, and until it is assimilated
at this level many of its potential benefits will not be
realized. However, when the opportunity has been
grasped the ICIDH has proved to be of great value,
including among groups of people who themselves have disabilities (10, 11).

On a second level the detailed classification schemes
for the three principal concepts serve to exemplify and
expand each of those concepts. Detailed cat-
egories are identified so as to facilitate structuring of
data. Here is where the ICIDH most resembles the
ICD, thus meeting WHO's original aspiration for a
framework against which information could be or-
duced so as to illuminate the consequences of
disease. Presumably rather formal statistical report-
ing was what was in mind, but unfortunately nothing remotely resembling information of this
type seems to be generated on a fairly routine basis—so that in this regard the ICIDH is waiting for
further empirical evidence to vindicate it. What was contro-
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pairment, disability and handicap, the justification
for which has been reviewed above. Differences
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(11, 13). Other variations were reinforced by the different professional contexts in
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habilitation facility and focus on physical capacity, while failing to indicate that mention and be
naively marketed—the individual without professionals in those areas. Such limitations be-
come especially critical when it is recalled that the largest proportion of people with disabilities live
in the community and are not in regular contact with individuals from any of the professional disciplines
with commitments to disability. The agenda func-
tion, in contrast, serves to remind those from any background of the topic areas to be taken into
account when in contact with someone with a dis-
ability. For example, the customary training of com-
ity nurses might not alert them to be sensitive
about the full range of disabilities, intellectual, be-
ha vioural, sensory, physical, or skill-related, and yet
as the likeliest contact with someone with a dis-
ability, all of these dimensions ought to be assessed, at least to the extent of discovering that someone
more expert in a particular dimension ought to be
consulted or called in.

The agenda aspect of the ICIDH has informed the
design of population surveys (14). It underpinned the
organisation and presentation of a guide to services
for physically disabled people in a metropolitan area (15); this was welcomed by both care profes-
sionals and people with disabilities. In somewhat
similar fashion the agenda has been exploited as a
proforma developed by the British Paediatric Associ-
ation to cover each single-digit category in the
ICIDH, and then used by a British health board in the
preparation of basic records for a computer register
of children with special needs (M. McCulloch, per-
sonal communication).

The fourth level of application of the ICIDH relates to
management functions. The first challenge for man-
agement is to take stock and analyse problems in
order to clarify their nature, so as to indicate the
types of input required to overcome or mitigate the
difficulties revealed. This aspect has already been
discussed at the first level, concerned with policy
formulation. Data are then needed which are re-
levant to the policies adopted, to which the second
and third levels refer. Finally, when policy has been
implemented, management will then wish to evalu-
ate the appropriateness and effectiveness of care
processes.

As discussed near the beginning of the introduction
to the ICIDH (1), the simplest requirement of a health
care-related taxonomy was that something—
though this is surely not too difficult. Under-
lying this, though, has been the perennial tendency
for health professionals to overmedicalize disable-
ment experience derivative, at least in part, from
the individualistic focus so common in Judaeo-Christian
cultures.

The latter element has been picked up by some
groups of people with disabilities, who have criti-
cized the ICIDH for being too individualistic. Who
wanted a scheme of classification that could be
applied to data on individuals, as happens with the
ICD. However, although directed at the functioning
of the individual the ICIDH nevertheless does pro-
vide means for establishing the social determina-
tion of disadvantage (13). On a deeper plane,
though, is the danger complementary to over-
medicalization, that of oversocialization (9). This
perspective often denies the relevance of the medical
condition underlying disablement, neglecting the
fact that this is the spring from which disability
emerges and that in all instances it accounts for a
significant, even if not necessarily overwhelming,
proportion of the variance in status. Such ideas are
often projected to what approximates to a con-
spiracy view of social interaction, seeing the dis-
advantage associated with disablement as the result
of social oppression (18). As a result the relevance
of work in the handicap area of the ICIDH is rejected.

At the root of both these extremes is the failure to
distinguish between tasks and roles. Tasks may be
the prerequisite for a role, but they are not sufficient
cause to be regarded as constitutive of the role; to
that extent there is a causal relationship between the
two, which answers one of the philosopher’s criti-
cisms (17). There is complex mediation between task
and role, to which individual behaviour and attitudes

Problems with the ICIDH

The fifth level at which the ICIDH has to be consid-
ered concerns its theoretical purity or appropriaten-
ness. Three years after the ICIDH was published a
critique by a philosopher was issued (17), question-
ning both the validity of the basic distinctions made
and whether the components were causally related
in the manner suggested. It was flattering that the
ICIDH merited serious consideration by a philo-
sopher, the basis for the challenge being essen-
tially linguistic. However, without wishing to appear
cavalier I would return to the point made earlier—the
justification of a taxonomy is whether it serves its
purpose, and growing use of the ICIDH despite
various difficulties (not in the main related to the
linguistic problems raised by the philosopher) attests
to fulfilment of some, at least, of the purposes.

Of greater concern has been what amounts to ide-o-
logical challenge. On the one hand, and perhaps the
most frequently encountered, has been diffidence
over straying into the domain of handicap or dis-
advantage, even though this is surely the most basic
level of classification. In this has been the attitude
on the supposed grounds that appropriate assess-
ment schedules or survey instruments are not pro-
vided in the ICIDH, notwithstanding that this was
beyond both the scope of WHO’s original briefing
and the resources available to undertake the neces-
sary developmental field work before the manual
was published. The range of information required to
distinguish between potential dis-
advantage, which the handicap code is intended to
reveal, and whether this is actually experi-
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cultures.
contribute as well as resources and social opportunities and restrictions; these points have been elaborated to generate information on the extent of disadvantage or handicap. These subtleties encouraged many to pursue their views on social oppression by seeking a consumerist platform as the remedy in a pluralist society. However, anti-welfare drifts in politics in both the United States of America and the United Kingdom, for example, have exposed the vulnerability of such rhetoric; consumerist demands face a bleak future when welfare budgets are reduced. In fact the acquisition of data through approaches such as the ICIDH should provide ammunition for endeavours to seek better social responses to disablement, by making explicit the extent of disadvantage or handicap. However, the value of such data will be jeopardized if attempts are made which in effect amount to suborning the ICIDH through unquestioning incorporation of the conspiracy view into its conceptual framework.

The way forward

Much of the progress in use of the ICIDH as a means of documenting the consequences of illness is reported in other contributions to this issue, in occasional papers in International disability studies (formerly International rehabilitation medicine), and in two series of papers arising from WHO working groups; the latter are enumerated in sources already cited above (12). The same sources examine some of the difficulties encountered, and common misconceptions about the ICIDH have also been identified (13). Responsibility for two problems, though, rests with WHO. Firstly, it is only recently that the Organization has done much to increase awareness of the possibilities extended by the ICIDH, to which development what collaborating centres have promovark in this area has been a welcome addition.

Secondly, many complain at what appears to be overlap between a number of items in the ICD and the ICIDH. Part of this relates to a difference in perspective. For example, incontinence is identified at 788.3 in the Ninth Revision of the ICD and it also features in the impairment code; this is not compatible with the ICD's intent to cover all medically-related conditions giving rise to morbidity or mortality in a single coding system, but equally incontinence is obviously an impairment which has to feature in any enumeration of disease consequences. Additionally some of the overlaps could be eliminated fairly readily, by clarifying the focus of the ICD; the V Code, to be the Z Code in ICD-10, remains at least equally problematic in this regard. Some of the apparent replication could be resolved more simply, by altering the emphasis in terminology as had been done in distinguishing between certain impairments and related disabilities (ICIDH, p. 33) (1). It is unfortunate that the processes leading up to the Tenth Revision of the ICD have not confronted these problems more systematically, so that needless duplication and perhaps attendant ambiguity will persist for the foreseeable future.

Such considerations apart, it will probably be helpful to give an indication of how what has proved to be the most off-putting part of the ICIDH, the handicap code, can be approached. This will be done by an outline of how my colleagues and I translated the physical independence dimension of handicap for application in a community survey (20); this will be reported more fully elsewhere (21). Again, the key to the approach lay in utilizing relatively standard data from enquiries about activities of daily living but viewing them from the perspective of handicap so as to generate information in keeping with the commissioning health and municipal authorities' principal concern with physical independence handicap.

Much experimentation was called for in the attempt to relate various functional difficulties to the most appropriate categories on an expansion of the physical independence handicap scale that we developed. The data base included pain and energy scores from the Nottingham Health Profile (22), although these were ultimately shown to contribute little useful to discrimination between categories. In the process it was found that many daily living activities were neutral as regards discrimination, and yet others functioned poorly for this purpose. At the end it was found that only 28 ADL variables, 41% of those originally considered, were necessary for assignment to categories on our expanded physical independence scale; i.e. a considerable reduction in the data needed was possible. The results were validated by independent assessments relating to a summary of dependence made by the interviewer and concept of an attendance allowance (a social security benefit for those needing constant attendance for at least 12 hours by day or night). This exemplifies how at least this component of the handicap code can function for the purpose for which it was designed, to ascertain the circumstances of people to indicate the risk of experiencing disadvantage.

At this juncture it is opportune to emphasize a fundamental point about information. Data tend to be regarded rather narrowly and in a particular light determined by the context and format in which they were originally collected. However, when looked at differently the same information can in fact serve to illuminate complementary aspects of a problem. The difference in perspective is accomplished by re-structuring the data; in other words, rearranging them to bring out similarities based on characteristics different from those which shaped the original structure of the data. Thus, as already mentioned, if ICD-derived data are restructured according to disabling potential rather than morbidity anatomy it is possible to learn something useful about disablement. Similarly, data on ADL gathered specifically in the context of disability can, when viewed differently, also serve to reveal the potential for disadvantage or handicap.

Up until now the ICIDH appears to have been used by only scattered and isolated individuals or groups, with the exception of participants at the WHO working groups held at Voorburg (Netherlands) (referred to above). However, the basic ideas have much wider currency, having been introduced into a number of textbooks and standard reference works; this is especially evident in Northern America. Unfortunately those who learn of the conceptual distinctions from these secondary sources remain largely unaware of the manual from which they were derived, so that practical application of the classifications does not proceed space. Part of the difficulty is that WHO publications are often far from easy to obtain, there usually being only a single main supplier in any country and conventional booksellers being largely unaware of the publications and how to secure them.

There does now seem to be growing awareness and utilization of the ICIDH, and initiation of WHO collaborating centres will hopefully extend this process.
The publication of the official French translation of the ICIDH late in 1988 (23) seems to be a watershed event in the wider application of the classifications—an appropriate landmark at the bicentenary of the French Revolution. However, the development is still really only in its infancy, because the wider implication of the ICIDH is to challenge the way in which arrangements for health care and social welfare are conceived at present (24), a process that has barely begun.

**SUMMARY**

The International Classification of Impairments, Disabilities, and Handicaps (ICIDH) was developed as a means for measuring the impact of illness and its consequences, although there was much delay before the classifications became at all well known. After giving an outline of how the ICIDH came into being, this article considers the basis of different types of health problem and of the potential of the International Classification of Diseases (ICD) and the ICIDH to reveal useful information on such problems. The ICIDH is based on a tripartite distinction between impairment, disability and handicap. It can be used as a resource at four different levels—for enlightenment about the nature of disablement problems and how they might relate to policies and services; as three detailed classification schemes to facilitate structuring of data about impairment, disability and handicap respectively; as a framework which provides an agenda for appraisal and assessment; and for facilitating management functions, perhaps especially the evaluation of care. Philosophical and ideological criticisms of the ICIDH are discussed, and means for applying what has proved to be the most controversial component or dimension, the handicap code, are illustrated. At the root of many difficulties is people's failure to appreciate that the same pieces of information can be used to illuminate complementary aspects of problems when the data are regarded from different perspectives. Further experience along the lines currently being undertaken should not only resolve many of the difficulties, but should also encourage more widespread adoption of the approach underlying the ICIDH.

**Résumé**

Mesure des conséquences des maladies

La Classification internationale des handicaps: déficiences, incapacités et désavantages (CIH) a été établie pour mesurer l'impact des maladies et leurs conséquences, même si beaucoup de temps s'est écoulé avant que les classifications n'acquièrent une certaine notoriété. Après avoir brièvement exposé les origines de la CIH, l'auteur de cet article évoque la base des différents types de problèmes de santé et des possibilités qu'offrent la Classification internationale des maladies (CIM) et la CIH pour l'étude de ces problèmes. La CIH repose sur la distinction entre déficiences, incapacités et désavantages. Elle peut être utilisée à quatre niveaux différents — pour donner des éclaircissements sur la nature des handicaps et la façon dont ils intéressent les politiques et les services; pour fournir trois systèmes détaillés de classification facilitant la structuration de données sur les déficiences, les incapacités et les désavantages; comme cadre offrant un calendrier pour l'appréciation et l'évaluation; et pour faciliter certaines fonctions de gestion et peut-être tout particulièrement l'évaluation des soins. Les critiques d'ordre philosophique et idéologique adressées à la classification sont évoquées et les moyens d'appliquer ce qui s'est avéré l'élément le plus controversé de l'ouvrage, le code des désavantages, sont illustrés. De nombreuses difficultés tiennent de ce que l'on ne se rend souvent pas compte que les mêmes éléments d'information peuvent servir à éclairer des aspects complémentaires des problèmes lorsque les données sont envisagées sous des angles différents. Une plus grande expérience dans la voie actuellement choisie devrait non seulement résoudre beaucoup de ces difficultés mais encourager aussi une utilisation plus générale de l'approche qui est à l'origine de la CIH.

**REFERENCES—RÉFÉRENCES**


