International Classification of Impairments, Disabilities, and Handicaps

A manual of classification relating to the consequences of disease



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INTRODUCTION

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INTRODUCTION

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 for the solution of these problems. Choices are being made all the time, even if only by default. It is assumed that the quality of choices would be enhanced if the degree to which decisions were related to information, a description of the situation as it is, was increased. The classification schemes in this manual are offered as frameworks to facilitate the provision of such information.

Information relevant to health experiences

The material incorporated in this manual is concerned with dimensions of health-related experience complementary to those embraced by the concept of disease. The manual is published by the World Health Organization, albeit only for trial purposes, in response to a resolution of the World Health Assembly. Inescapably, this carries with it the implication that information about these additional dimensions is useful and even necessary for health service planning. As the collection of this extra information can only increase the burden on existing information systems, it is prudent to begin by indicating why the need for it arises.

Routinely available data

The organization and planning of a health care system are generally based on information generated routinely from the system. This tends to be of two types. First, there are indicators of need, such as recorded morbidity experience. Second, there are data that are the by-products of administrative requirements; these consist of information on resource inputs, such as manpower or hospital beds, or derivatives from these such as waiting lists, and on resource utilization, such as patient loads in various sectors of the system.

All this information is the product of an existing health care system, and it is therefore subject to the same assumptions as those underlying available health care processes. In other words, questions of utility and relevance, as they concern the appropriateness both of the care system and of the inform-

ation that derives from it, are difficult to examine. This means that the potential for fundamental appraisal or evaluation of the processes is very limited, and as a result alternative approaches may too readily be neglected.

If health care processes are to be evaluated, they must be goal-oriented, because the appraisal is concerned with the extent to which goals are attained. The prime requirement is for clearly specified outcome goals. This would permit study of the extent to which these outcome goals are met, the effectiveness of the particular health care process; the inputs necessary to attain this, the efficiency of the process; and its availability and uptake, the equality of its distribution. ¹ Management is always likely to be processing data on resource provision and utilization but, as should be evident, these are relevant mainly to efficiency and equality goals. Although attempts have been made to evaluate effectiveness by these means, resource data can serve only as proxies for what is of real concern.

Data for evaluation

Three aspects are fundamental to any attempt to evaluate the effectiveness of health care processes. These are:

- i) contacts made with the system;
- ii) how the system responds to contact; and
- iii) the outcome of contact.

Assessment of the second of these, how the system responds to contact, requires only brief consideration. In principle the means for structuring information relevant to this aspect are widely available. Thus resource data of the types already indicated can be used for global appraisals, whilst the newly developed International Classification of Procedures in Medicine 2 provides a framework for documenting specific responses by the system. However, the nature of information pertinent to the first and third aspects is less straightforward and therefore requires more detailed examination.

The outcome of contact has to be related to goals. In general, these have not been formulated with the precision necessary to permit evaluation. However, the simplest requirement of a health care system is that some beneficial change in the individual's situation or status should result from contact with the system. If no such change can be detected, then the value

^{1.} Cochrane, A. L. (1972) Effectiveness and efficiency: random reflections on health services. London, Nuffield Provincial Hospitals Trust.

^{2.} World Health Organization (1978) International classification of procedures in medicine, Geneva, vol. 1 and 2.

of a given health care process is seriously open to question. Thus, the challenge is to devise a means of describing the status of an individual in such a way that, by assessing status when contact is first made and then again after the system has responded, change can be recorded. This change would provide a measure of outcome.

Unfortunately, the nature of the challenge alters as the burden of morbidity changes. Thus when the major force of disease is expressed as acute illness, of which the acute infections provide the most notable example, simple and unequivocal measures are readily available from which outcome can be assessed. These consist of the occurrence or otherwise of the disease, and recovery or a fatal outcome. For this purpose, terms derived from the International Classification of Diseases (ICD) provide a valuable and relevant means for studying health experience, and the underlying cause concept is additionally helpful. Moreover, generalizations in population terms are simple to derive and are justifiable because disease control is so dependent on community-based action. Herein lay the nineteenth-century foundations of public health and of the value of indirect indicators of community health, such as perinatal mortality.

As the acute infections come under control, other diseases assume a greater importance. As long as the latter are life-threatening, the simple indicators, such as mortality, continue to be valuable, so that ICD terms retain their usefulness for evaluation. However, as technological power is developed, the situation changes. Conditions like diabetes and pernicious anaemia can be controlled even though their underlying causes cannot be eliminated. Mortality and even the occurrence of disease then have less relevance to evaluation other than that relating to primary prevention, and ICD terms no longer reflect outcome goals, particularly when the rules for assignment to categories are constrained by the underlying cause concept. Hence the need to identify manifestations, a facility made possible by options in the Ninth Revision of the ICD. This extension of the classification does permit evaluation, because of the potential for a manifestation to be abolished or suppressed; change after contact can thus be recorded. However, the extent to which population generalization can be developed on this basis remains to be explored further.

Diseases that are self-limiting or amenable to prevention or cure account for only part of the spectrum of morbidity. In fact, the very success of control measures for these diseases has resulted in the increasing importance of a residue of conditions that do not come into this category. These include the effects of trauma, impairments of special sense organs, mental retardation and mental illness, and the chronic diseases of middle and later life, particu-

larly heart disease, stroke, bronchitis, and arthritis. Disorders like these are coming to dominate current morbidity experience in some countries and they are especially noteworthy as causes of disability. For these disorders, a manifestation code is very useful for identifying the calls that may be made on different types of service, but it can only rarely serve as a means of indicating change in the individual's status after contact with a health care system.

Consequences of disease

The difficulties arise because of the limited scope of the medical model of illness. The kernel of the situation is represented by the concept of disease, which may be depicted symbolically as a sequence,

etiology — pathology — manifestation.

The ICD is based on this model, the components of the sequence being variously and severally identified within the classification. However, such a model fails to reflect the full range of problems that lead people to make contact with a health care system. Some consideration of the nature of the reasons for contact is therefore necessary.

Sickness interferes with the individual's ability to discharge those functions and obligations that are expected of him. In other words, the sick person is unable to sustain his accustomed social role and cannot maintain his customary relationships with others. This view is sufficiently broad to take account of the vast majority of calls that are likely to be made on a health care system. At one extreme, it embraces life-threatening disease, and, at the other, it includes less medical experiences such as anxiety or the wish for advice and counselling. The only class of contact not incorporated in this approach is contacts made in the absence of illness phenomena, such as attendances for prophylactic inoculation. Provision for certain of these non-sickness-related contacts has been made ever since the Sixth Revision of the ICD, and this aspect has now been tackled systematically in the Ninth Revision (Supplementary Classification of Factors influencing Health Status and Contact with Health Services — V Code).

Although, in everyday practice, the medical model of illness portrayed above provides a very efficient approach to disorders that can be prevented or cured — the impact of illness is relieved secondarily as the underlying condition is brought under control — it is incomplete because it stops short of the consequences of disease. It is the latter, particularly, that intrude upon everyday life, and some framework is needed against which understanding of these experiences can be developed; this is especially true for

chronic and progressive or irreversible disorders.

The sequence underlying illness-related phenomena thus needs extension. This can be presented as

disease handicap

The nature of these different dimensions of the consequences of disease, their definition, and the basis for developing three separate classification schemes, will be considered in greater depth in the first section of this manual. At this juncture it is probably sufficient to note that the distinctions facilitate policy development in response to the problems, clarifying the potential contributions of medical services, rehabilitation facilities, and social welfare respectively. By the same token, the proposals offer different types of status descriptor, with a varying potential for change, so that the needs of evaluative studies are anticipated. Furthermore, the descriptors provide the basis for study of both the reasons why an individual makes contact with a health care system and a related problem, underutilization, where it is the determinants of why not all of those with a given health status make contact with the system that are of interest.

Development of the classifications

Many approaches have been made to measurement of the consequences of disease. One strand has been concerned to structure experience in clinical and rehabilitation contexts, and this has been particularly notable in the United States of America. Great emphasis has generally been placed on functions such as activities of daily living, and the approach has been based on assessment procedures.³ A more recent development has sprung from demands for ascertainment of disabled individuals, either in prevalence surveys or for determining eligibility for pensions and other welfare provisions. The purpose has been to identify categories or groups of people fulfilling predetermined criteria; works of this type have therefore been concerned more with assignment than with assessment. However, the range of applications has been considerable, extending from routine health statistics and specific cash benefits to health service planning, social security, social administration, and social policy.

Those concerned with measurement on a community scale, by the gathering and presentation of statistical tabulations relevant to these purposes,

^{3.} Wood, P. H. N. & Badley, E. M. (1978) An epidemiological appraisal of disablement. In: Bennett A. E., ed., Recent advances in community medicine, Edinburgh, Churchill Livingstone.

were stimulated by these activities. A preliminary scheme was developed by Mrs Esther Cahana, and submitted to WHO by Israel in 1972. Within a few months, a more comprehensive approach was suggested by the WHO Centre for the Classification of Diseases, in Paris, after discussions between the Head of the Centre, Dr Madeleine Guidevaux, and Professor André Grossiord of Hôpital Raymond Poincaré, Garches, France. These suggestions were based on two important principles: distinctions were made between impairments and their importance, i.e., their functional and social consequences, and these various aspects or axes of the data were classified separately on different fields of digits. In essence, this approach consisted of a number of distinct, albeit parallel, classifications. This contrasted with the traditions of the ICD, wherein multiple axes (etiology, anatomy, pathology, etc.) are integrated in a hierarchical system occupying only a single field of digits.

WHO therefore invited a consultant, Dr Philip Wood of Manchester, England, to explore the possibility of assimilating the Paris proposals into a scheme compatible with the principles underlying the structure of the ICD. For this purpose, it was intended to supplement a three-digit hierarchical classification of impairments, analogous in form to the ICD, by three additional digits dealing with disability and handicap in the form of mobility, physical dependence, and economic dependence. At the same time, preliminary attempts were made to systematize the terminology applied to disease consequences. These suggestions were circulated informally in 1973, and help was solicited particularly from groups with a special concern for rehabilitation.

It soon emerged that difficulties arose not only from nomenclature, but also from confusion about the underlying concepts. After clarification of these ideas, it became apparent that a single scheme conforming to the taxonomic principles of the ICD was unsatisfactory. Whilst impairments could be dealt with in this manner, a synthesis of the different dimensions of disadvantage could be accomplished only by making arbitrary and often contradictory compromises between the various dimensions or roles identified. The principle was therefore advanced that a classification of handicap had to be structured differently, based on ordination of the different states of each dimension. This development is discussed in greater detail in the first section of this manual.

After discussions with Professor Grossiord and the Paris centre, separate classifications of impairments and handicaps were prepared. These were circulated widely in 1974, and many comments and suggestions for improve-

ment were received. Particularly helpful contributions to the development of these schemes have been made at various stages on behalf of the International Continence Society (Eric Glen), the International Council of Ophthalmology (August Colenbrander), the International and European Leagues against Rheumatism (Philip Wood), the International Society for Prosthetics and Orthotics (the late Hector W. Kay), and Rehabilitation International (K.-A. Jochheim). Acknowledgement must also be made to the individual contributions of Elizabeth M. Badley and Michael R. Bury, and to the work of Bernard Isaacs and Margaret Agerholm. Various memoranda were also made available by the World Health Organization, both at its headquarters in Geneva and at its Regional Office for Europe in Copenhagen.

Further discussions were then held, involving WHO and representatives of the International Social Security Association and the Social Security Department of the International Labour Office. Responsibility for collating comments and developing definitive proposals was undertaken by Dr Wood. These were submitted for consideration by the International Conference for the Ninth Revision of the International Classification of Diseases in October 1975. At this juncture the scheme incorporated a supplementary digit to identify disability, and the whole approach was acknowledged as being to a large extent experimental and exploratory. Having considered the classification, the Conference recommended its publication for trial purposes. In May 1976, the Twenty-ninth World Health Assembly took note of this recommendation and adopted resolution WHA 29.35, in which it approved the publication, for trial purposes, of the supplementary classification of impairments and handicaps as a supplement to, but not as an integral part of, the International Classification of Diseases.

The present manual, published under this authority, represents a considerable recasting of the detailed proposals submitted to the Ninth Revision Conference. The hierarchical arrangement of the impairment classification has been radically altered so as to allow for taxonomic spaces more closely related to importance and frequency of occurrence; a completely new disability classification has been introduced, resembling in structure the impairment classification; and the handicap classification has been augmented. These alterations have been carried out in the light of preliminary field testing, comments by the International Federation of Societies for Surgery of the Hand (Alfred B. Swanson), and further comments by the individuals and organizations noted previously and by UNESCO and OECD.

Practical application of the classifications

Scope and structure of the manual

The manual contains three distinct and independent classifications, each relating to a different plane of experience consequent upon disease.

- (a) Impairments (I code), concerned with abnormalities of body structure and appearance and with organ or system function, resulting from any cause; in principle, impairments represent disturbances at the organ level.
- (b) Disabilities (D code), reflecting the consequences of impairment in terms of functional performance and activity by the individual; disabilities thus represent disturbances at the level of the person.

These two are perhaps the least controversial. Their taxonomic structure resembles that of the ICD in that they are hierarchical, with meaning preserved even if the codes are used only in abbreviated form; also they are exhaustive. The contrast between the I and D codes stems from the nature of what is being classified. Impairments resemble disease terms in the ICD in that they are best conceived of as threshold phenomena; for any particular category, all that is involved is a judgement about whether the impairment is present or not. On the other hand, disabilities reflect failures in accomplishments so that a gradation in performance is to be anticipated; provision has thus been made for recording of the degree of disability, and also of future outlook.

(c) Handicaps (H code), concerned with the disadvantages experienced by the individual as a result of impairments and disabilities; handicaps thus reflect interaction with and adaptation to the individual's surroundings.

Handicap is more problematical. The structure of the H code is radically different from all other ICD-related classifications. The items are not classified according to individuals or their attributes but rather according to the circumstances in which disabled people are likely to find themselves, circumstances that can be expected to place such individuals at a disadvantage in relation to their peers when viewed from the norms of society. The scheme is not exhaustive and is restricted to key social roles, what have been regarded as the most important dimensions of disadvantageous experience—orientation, physical independence, mobility, occupation, social integration, and economic self-sufficiency. For each of these dimensions a gradation of circumstances is possible, so that specification of the individual's status in regard to each is required. These properties determine that the codes are not hierarchical in the customarily accepted sense, and abbreviation is possible only by neglecting certain of the dimensions. Perusal of the outline of the H code should indicate these characteristics more clearly.

These and other features of the three classification schemes are examined at greater length in the first section of the manual. Assessment and assignment to relevant categories are also discussed. In addition, the manual includes an index to impairments.

Data sources

With the exception of surveys and research enquiries, the primary source for data of the type covered by this manual is the records of contacts made with a care system. It is therefore necessary to review what is entered in records, so that its suitability for classification according to the present schemes can be considered. Contact will be made with a caring professional, who may be a physician, a nurse, a remedial therapist, a social worker, or a pensions assessor, or who may be from various other health-related professions. The essence of the transaction that ensues is that the individual's problems are elicited and assessed. The conclusions of the assessment, augmented by some of the information exchanged, are likely to be noted in the case records.

The process may be exemplified by medical diagnosis. Symptoms and signs are elicited from the individual. These are then assessed and considered in conjunction. On the basis of known constellations of characteristics it is usually possible to assign the individual's problems to a predetermined group or category in the form of a specific diagnosis. Three aspects are especially noteworthy. First, the raw data are individual-oriented, the symptoms and signs present in one specific individual. In terms of an information system all that can be derived are enumerations of individuals with particular attributes. Second, meaning is given to these diverse attributes by categorization, identifying a basis for interrelationships between them. This generates group-oriented information, which has two important properties. There is a potential to make inferences about individuals in the group that go beyond the limits of data necessary for categorization; for instance, in addition to labelling the individual's collection of symptoms and signs an ideal diagnosis also indicates etiology, pathology, and prognosis. There is also a potential to aggregate category-oriented data on the basis of more general commonalities, such as the chapters of the ICD, and this enhances transmission of simplified information. The third significant aspect of medical diagnosis is that it provides a medium for communication between one professional and another, largely on the basis of the attributes that can be inferred from the category label.

On this foundation, it is possible to examine the nature of information likely to be available on disease consequences. A number of difficulties are immediately apparent, and their influence can most clearly be revealed by pursuing the analogy with medical diagnosis. First, objectives inevitably differ appreciably between the various professions; thus what is germane for a remedial therapist is unlikely to be so for a social worker. This variation in emphasis and concern introduces a lack of comparability into data. Second,

heterogeneity tends to be exaggerated by the fact that in this context most professions are concerned mainly with assessment and its associated individual-oriented data, without there having been much standardization of procedures. Information of this type does not lend itself to simplification for transmission in an information system; consider, for instance, an enumeration of difficulties experienced in the activities of daily living, which is not particularly helpful either for service planning or for indicating policy options.

A third difficulty is that unifying concepts analogous to disease entities have not generally been developed. As a result few category-oriented data have been available, an important factor contributing to shortcomings in policy development and planning in regard to the disabled. Finally, the lack of appropriate concepts with transprofessional currency has led to communication difficulties, a problem compounded by ambiguity and confusion in terminology.

This manual does not presume to resolve all these difficulties, as its publication for trial purposes indicates. However, it is presented for exploration as a means of overcoming some of the problems. It seeks to contribute to the promotion of uniformity in broad concepts and terminology and, by indicating ways in which individual attributes may be grouped together for simplification, to encourage standardization and an improvement in the comparability of data. Today's case records are unlikely to contain all the necessary detail in a form suitable for rigorous application of the classification schemes. Nevertheless, it is hoped that the manual will have educational value, stimulating the collection and recording of more appropriate data.

Pending the gathering of more ideal information with these classification schemes specifically in mind, it is still possible to exploit the approach with existing records. Some indication of the possibilities may be helpful. The underlying cause of an individual's difficulties, the disease, can usually be ascertained from the diagnosis stated in medical records, so that ICD coding is not too difficult. In nonmedical records the underlying cause may not be easy to determine, but in these contexts it is usually likely to be of less importance in any case. In either type of record the more immediate consequences of disease, the major impairments, are likely to be noted, so that coding to the I code should also not present insuperable obstacles. The main aspect likely to command attention in the future relates to identification criteria and their relation to severity.

The D code calls for information that is also likely to be in the records already, although care will be necessary in regard to variation resulting from