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THE ICIDH-2 - USING THE CLASSIFICATION FOR STATISTICS AND RESEARCH

Invited paper submitted by the Office of National Statistics, London [1]

Summary

The World Heath Organisation is in the process of revising the International Classification of Impairments, Disabilities and Handicaps (ICIDH). This paper describes the background to the ICIDH and the new features of the revised classification in relation to its aims and applications. The ICIDH has been extensively used in prevalence studies of disability and to measure the effectiveness of rehabilitation and examples of some of these studies are cited. The paper concludes with the plans for the future development of the ICIDH and the particular problems in translating the underlying concepts into assessment instruments that can provide valid and reliable data for research and statistical purposes including comparative studies.

[1] Prepared by Howard Meltzer.

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1. Background

In 1980, the World Health Organisation (WHO) issued the International Classification of Impairments, Disabilities and Handicaps (ICIDH) to promote a common framework and definitions of disability-related issues. [1] The launch of the ICIDH was an attempt to encourage health researchers and statisticians to use a more precise, objective and internationally recognised terminology to replace the often imprecise and pejorative terms which had previously been used.

During the 1980s countries such as Australia, Canada, Great Britain, the Netherlands, Spain and the United States started to collect data in accordance with ICIDH principles and terminology, and more recently, other countries have been referring to the ICIDH in their national collection of disability data through censuses and surveys.

In the 1990s the World Heath Organisation initiated a major revision of the ICIDH reflecting fundamental changes in the concept of health - moving from a medical model concerned primarily with the individual to a more interactive interpretation encompassing biological, social and environmental influences. Although the new version of the ICIDH has as its full title, the International Classification of Impairments, Activities and Participation, it is referred to in short as the ICIDH-2 reflecting its debt to the original version.[2]

2. Key concepts of the ICIDH-2

In the ICIDH-2, Impairment is defined as a loss or abnormality of body structure or of a physiological or psychological function.

Activity is described as the nature and extent of functioning at the level of the person and may be limited in nature, duration and quality.

Participation is the nature and extent of a person's involvement in life situations in relations to Impairments, Activities, health conditions and contextual factors. Like Activities Participation may be restricted in nature, duration and quality

The impairment classification is divided into sections, one dealing with function, the other with structure. Each section has ten chapters with a corresponding chapter in each section dealing with a particular bodily system. The functional systems are:

Mental functions
Voice, speech, hearing and vestibular functions
Seeing functions
Other sensory functions
Cardiovascular and respiratory functions

Digestive, nutritional and metabolic functions
Immunological and endocrinological functions
Genitourinary functions
Neuromuscular, skeletal and movement related functions
Functions of the skin and related functions

At the broad chapter heading level , Activities are classified as:

Seeing, hearing and recognising
Learning, applying knowledge and performing tasks
Communication activities
Movement activities
Moving around
Daily life activities
Care of Necessities and Domestic Activities
Responding to and dealing with particular situations
Use of technical devices, technical aids and other related activities

The classification of Participation has seven main chapter headings

Participation in personal maintenance
Participation in mobility
Participation in exchange of information
Participation in social relationships
Participation in the areas of work, leisure and spirituality
Participation in economic life
Participation in civic and community life

The new version of the ICIDH is more complex, comprehensive and coherent than its predecessor and poses quite daunting challenges to those involved with its development and implementation. Although the three concepts, impairments, activities and participation are inter-related there is no reason why each part of the classification can not be used separately. Similarly, some researchers may have questions which may only relate to certain aspects of each of the three primary domains.

3. Aims of the ICIDH-2

The purpose of the ICIDH-2 is to provide a common framework and an overarching perspective for describing, understanding and communicating about the consequences of ill-health. It is a multi-purpose classification designed to serve various disciplines. The principal aims of the ICIDH-2 as stated in the draft manual are:

- To provide a scientific basis to understand and study the consequences of health conditions

- To establish a common language for describing consequences of health conditions in order to improve communication between health care workers, other sectors and people with disabilities

- To provide a basis to understand the impact of disablement phenomena on the life of individuals and their participation in society

- To define consequences of health conditions in order to provide better care and services to improve the participation in society of people with health conditions

- To permit comparison of data across countries, health care disciplines, services and time

- To provide a systematic coding scheme for health information systems

- To stimulate research on the consequences of heath conditions

- To collect data on facilitators and inhibitors in society that affect the participation of people with disabilities

[illegible]
Assessment Schedule) and the ICIDH-2 Checklist.

4. The applications of the ICIDH-2

[illegible] been used for various purposes and

- As a statistical tool - epidemiological or population surveys, information-gathering questionnaires for demographic purposes, database development, management information systems.

- As a research tool - measuring health, rehabilitation and social integration outcomes, assessing quality of life

- As a clinical tool - needs assessment, matching treatments with specific conditions, personalised treatment plans, evaluation of treatment outcomes

- As a social policy tool – assessment of eligibility for social security payments, disability insurance, compensation systems

- As an educational tool – curriculum design, public awareness, promotion

Another way of categorising the application is to look at the uses of the
ICIDH-2 in terms of the unit of analysis:

- At an individual level (for example, to identify a person’s need for treatment);

- At a service level (for example, to document the utilisation of services or the effectiveness of interventions to develop heath care policies);

- At a population level (for example, to identify societal needs for specific policies and priorities for health and welfare systems)

A third way of classifying the applications of the ICIDH-2, i.e. additional to discipline and unit of analysis is by health problem: stroke patients, those with sight, hearing or speech problems, people with psychiatric or neurological problems.

As a multi-purpose instrument, the ICIDH-2 has to be able to deal with the consequences of health problems for children and adolescents and for elderly people. Children and adolescents pose assessment problems owing to the need to take account of developmental stages. The problem with looking at the impairments, activities and participation of elderly people is that ageing increases the likelihood of multiple health problems which can cause restrictions in activities and participation in several domains.

Mental health issues also present problems in the application of the ICIDH--2 because it is sometimes difficult to distinguish between the disorder and its consequences

5. Specific uses of the ICIDH-2

Because the ICIDH-2 is still in its development stages, the illustrative examples described below are based on statistical research carried out with the original version of the ICIDH as the underlying conceptual framework. Therefore, they tend to focus on disability or restrictions in activities rather than on participation. However, what a review of the ICIDH-based research does show is how the problems encountered with these studies have helped to inform the revision process. The most extensive use of the ICIDH has been in prevalence studies and in the field of rehabilitation.

Prevalence studies

The framework and definitions of the ICIDH have been used in disability surveys at national, regional and local levels in several countries to

estimate the prevalence of disability. The main purpose of most prevalence studies, which have used the ICIDH as the basis for their assessment schedules, has been to estimate the prevalence of disability (and gross estimates) by age and sex, to identify the impairments which give rise to the disabilities, and to look at look at the limitations in day to day activities (participation) associated with the impairment and disability.

The prevalence rates of disability reported by national studies have been very similar: Canada (1986): 15.5% ; Great Britain (1985) 14%; Spain (1986) 15%.[3,4,5] Despite these similar figures, several problems in carrying out disability assessments have been documented in the reports on these prevalence studies.

(a) Difficulty in getting ratings on every item in the classification.
(b) Getting a consensual understanding of terms
(c) Collating all data to get an overall prevalence rate
(d) Getting respondents with multiple disabilities to say what impairment was associated with which disability
(e) Coping with conditions which vary in duration and severity
(f) Measuring disability with or without the use of technical aids and personal assistance.

Most national survey data on disability are archived and these data are a vital source for secondary analysis. As more data have been collected from surveys based on the ICIDH, there has been a burgeoning in the analysis of what is called disability-free or handicap- free life expectancy or heath expectancy. Such analysis has been carried out in Australia, France, Great Britain, Spain and the Netherlands. [6]

Rehabilitation

Not surprisingly , the ICIDH has been extensively applied to the field of rehabilitation because both the classification and the medical discipline are concerned with the consequences of disease. In ICIDH terminology, the purpose of rehabilitation is to try and reduce the disabilities and handicaps associated with impairments. An initial ICIDH assessment of an individual with, for example, spinal injury, arthritis or poor vision, can establish his/her degree of need for rehabilitation and suggest which interventions and services are most appropriate (physiotherapy, occupational therapy, etc.) Repeated assessments can indicate whether the individual is improving with the use of services.

Most of the cited examples of the use of the ICIDH in rehabilitation are at the individual level (patient profile, assessment of patient needs, evaluation of treatment or discharge status). However, there have been studies which have looked at the evaluation of treatment at the institutional level and the need for staff at establishments who carry out rehabilitation. There are also a few examples where the ICIDH has been used to inform policy,

particularly on the education and training of professionals and community-based rehabilitation programmes. [7]

6 The future of the ICIDH-2 in statistics and research

One of the great advantages of having a multi-purpose classification which aims for a common terminology and a conceptual framework is that disability statistics can be compared across regions within countries and between countries. However, a brief review of the research carried out shows that those carrying out the studies have chosen those parts of the classification that suit their needs. This is why the WHO are trying to produce various types of assessment schedules based on the ICIDH-2 which can be used for various purposes in a variety of settings. Undoubtedly, there will be a push from users to have these instruments available in a computerised form.

There has also been some concern expressed about finding a more systematic way of measuring severity in relation to limitations in activity and participation. This in turn would enhance the likelihood of developing algorithms which could be applied to the data to yield for example an overall measure of disablement or eligibility for the receipt of benefits.

The main challenge ahead will be establishing the criteria to measure the participation domain as this takes account of the social, cultural. religious and political realms of life.

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