ARCHIVES OF DISEASE IN CHILDHOOD

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Annotations

The classification of disability

'When I use a word', Humpty Dumpty said in rather a scornful tone, 'it means just what I choose it to mean, neither more nor less'.

> *Through the Looking Glass*, by Lewis Carroll.

In classifying disability there are six linked concepts.

(A) Disease disorder or damage.

(B) Loss or abnormality of psychological or physiological or anatomical function: due to A.

(C) Restriction or lack of ability in expected human activity: due to A or B.

(D) Disadvantage that limits or prevents fulfilment of expected social roles: due to B or C.

(E) Disadvantage that limits or prevents fulfilment of expected social roles: due to F.

(F) Social structure, attitudes, and resources: related to A.

The problem is not the concepts themselves but the labels we attach to them.

Medical model

This evolved in the 1970s, suggesting names for concepts (A) to (D). Concept (A) is the subject of the *International Classification of Diseases* (ICD) now in its 10th revision. There were attempts to extend the ICD coding system by adding additional numbers within each field to include disability and handicap, but this was found to be impractical.[1] The ICD was unable to reflect the complexity of the consequence of disease. Philip Wood, a rheumatologist from Manchester, evolved a new classification. It has separate codes for impairment, disability, and handicap. In 1976 the World Health Organisation (WHO) published this, under the title of the *International Classification of Impairments, Disabilities and Handicaps* (ICIDH).[1]

(A) disease or disorder
↓
(B) impairment
↓
(C) disability
↓
(D) handicap
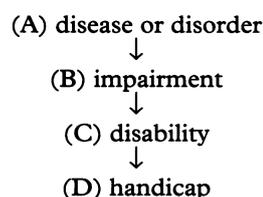
The ICIDH left concept (E) unnamed. Its view of concept

(F) was that though cultures varied, a person's environment was an unchangeable background. It was 'life'.

The concept of *normalisation* become popular as part of the medical model and the establishment of community mental handicap teams. The idea, radical at the time, was that people with learning disabilities should wherever possible receive services in ways that were normal for society and that made them as normal as possible.

Social model

At the same time a view was forming among adults with disability[2]: '*While we may have medical conditions, which hamper us and which may or may not need medical treatment; human knowledge technology and collective resources are already such that our physical or mental impairments need not prevent us from being able to live perfectly good lives. It is society's unwillingness to employ these means to altering itself rather than us which causes our disabilities*'.

Within a social model individuals who are different by virtue of an impairment find that they are oppressed by a society obsessed with concepts of normality. In other words disability only exists in so far as it is socially constructed and imposed on people with impairments. This is diagramatically shown below:

(A) disease or disorder
↓
(B) impairment
↓
the person
↑
(E) disability
↑
(F) social environment
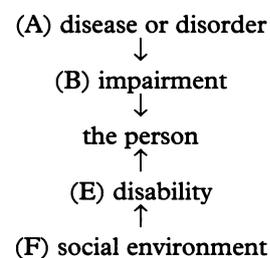
Concepts (C) and (D) were not named and (F), society, was seen as needing great change. This is the heart of disabled people's current fight for civil rights. The medical model has been the target of bitterness because it has been seen, particularly when the concept of *normalisation* was popular, as a force only to change disabled people into some more *normal* beings and not as a campaigning force for social change. On the other hand, many in medical and allied professions have viewed the social model as denial of

what is an objective truth about ability and a threat to their genuine attempts to make life better for people.

'*Disabled people need definitions of disability which they can accept and which are non-stigmatising. At the same time they need access to complex and expensive services and may need to prove maximum inability and dependence. This paradox is truly a challenge*'.

(Philippa Russell, director, Council for Disabled Children)
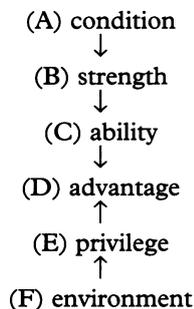
A combined model
It is time for both sides to come out of their trenches and embrace a larger model of disability. One which combines the concepts of the ICIDH with the experience of disabled people.

(A) condition
↓
(B) impairment
↓
(C) disability
↓
(D) disadvantage
↑
(E) discrimination
↑
(F) environment
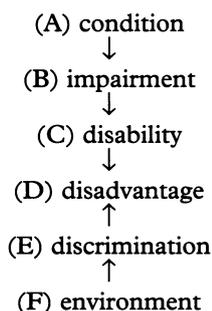
Thinking positively
We happily classify disability using a sequence of deficits. Yet a person's final state is a balance of both positive and negative. The combined disability model should be compared with its positive relative.

(A) condition
↓
(B) strength
↓
(C) ability
↓
(D) advantage
↑
(E) privilege
↑
(F) environment

Language
In order to communicate with others using a combined model there will need to be agreement on changes of language. Some words are ambiguous and some words have become unacceptable to people.

NORMAL
Doctors may like to think its meaning to be a statistical statement. However, the word normal also carries the meaning of acceptable. Disabled people want acceptance and therefore may reject being defined as abnormal. This one word with two meanings has great potential for misunderstanding.

DISABILITY
This word has been used by the ICIDH to mean the objective result of impairment, and by the disability rights movement to mean the disadvantage imposed by society on people with impairments. One word used for two concepts is a recipe for confusion. The word disability should be used in the ICIDH sense. When meaning imposed disadvantage people should consider using the words imposed disadvantage or discrimination (on grounds of ability).

DISABLEMENT
Some people use the word disablement as synonymous and arbitrarily interchangeable with the word disability. Others use disablement in the sense of the process which causes a loss of social role. It is something which is done to someone rather than the way they are. Some people say they use disablement in the sense of taking in a person's whole state rather than a particular part of them which is impaired. Both disability and disablement are nouns from the verb disable and all dictionaries give the two as synonyms. Disablement seems like an evolving word in search of a home or concept. While there is no agreement about a separate meaning for the word disablement, it would be best to use the word disability instead.

HANDICAP
The word handicap is said to have originated from 14th century horse racing when a rider of a good horse had to race holding his cap in one hand.[2] Handicap is therefore an imposed disadvantage but it also conjures images of dependence and pity. Although these images may have been seen as helpful or revolutionary in the 1930s when disabled people faced extreme denial of human rights, the social and political climate has gradually improved. Disabled people still have a long list of stereotypes to battle against and many now no longer wish the baggage that comes with the word handicap. It represents the societal views they see as oppressive and wish to change.

In writing the ICIDH Philip Wood used the word handicap in a precise sense to describe the interaction between a person with impairments and their unchanging environment. However, the lay use of the word predated the ICIDH and has changed little as a result of it. Many charities rely upon the continuation of old attitudes when fundraising. In spite of the fact that the ICIDH was written by doctors, the profession as a whole has also continued to use the words very loosely. For example, the word handicap continues to be used where the word disability would do. To say 'I am late for my handicap clinic' is unhelpful in two ways. Firstly the doctor's task is almost certain to be focused on the contribution of the impairment to the disability. Secondly there is the assumption that all children with impairments are automatically handicapped or handicap their family. This is untrue. The doctor, who is often amazed at the way in which some families, with the most disabled of children, value and accept that child unconditionally, is confronting that assumption within him or her self. It is also a misunderstanding of the ICIDH which clearly defines handicap as the mismatch between ability and expectation of ability when it used the concept of a normal role. If expectations were realistic and matched to ability there would be no handicap. Some readers may feel uncomfortable with this because it seems to fly in the face of traditional medical teaching. Comfort comes with a more comprehensive view of disability.

We should consign the word handicap to historical contexts, or be sure to use it strictly in the way it was defined within the ICIDH. In most clinical situations the word disability can be substituted for the word handicap without any change in meaning. When the word handicap is really being used, meaning the impact of disability on social roles, the word disadvantage can easily be substituted and is a choice which is less likely to offend and more likely to be accurately understood.

Read codes

In order to use computers in health care we must establish a standard language, which can be coded and handled electronically. The system being adopted in the UK is known as Read coding, named after its inventor, a doctor, James Read. Many specialties, including child health, are currently compiling lists of commonly used clinical terms. Within the field of disability this will include words used to describe a child's development and environment. A key principle is that of one concept covered by one word, as well as the recognition of duplicate or synonymous terms. This is another urgent reason to find agreement about the language and the definitions and the classifications we use.

Office of Population Censuses and Surveys (OPCS)

In the early 1980s Normal Fowler set up reviews of social security to look at supplementary benefit, housing benefit, retirement pensions, and benefits for children and young people. The government felt it did not have enough information about disabled people, their incomes and needs upon which to base these reviews. Social benefits are linked to the establishment of disability, and so it is a matter of public finance and great political importance to be able to establish rules of eligibility. In 1984 the Department of Health and Social Security commissioned a series of six questionnaire surveys. Thus in 1986 the largest UK attempt to collect population information in an ICIDH format was conducted.[3] Part of the methodology was the concept of disability as a continuum. The threshold above which people are considered sufficiently disabled to be counted had to be selected.
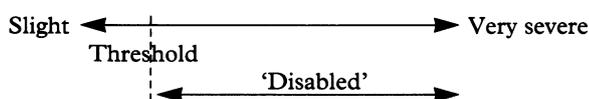
This needed some objective measures of severity. A panel of 'judges' were used to assign relative weightings to different abilities within one category such as mobility. They also assigned relative weightings between different categories. An overall score was achieved which enabled the disabled person to be assigned to one of 10 degrees of severity. The majority of disability was related to age. Once over the age of 85, 80% of the population had levels of disability over the selected threshold. The severity scores for the elderly have a pyramidal distribution with the greatest number being mildly affected and decreasing numbers with each increasing degree.

The overall prevalence of disability in childhood was found to be 3%. This represents 360 000 children under the age of 16. The highest single category was emotional and behavioural problems. There were children in similar numbers in all categories of severity of disability.

This was a research exercise, and though districts such as Lothian have tried, none has managed to turn the ICIDH codes into a practical working tool. The Children Act registration requirements have put new urgency into the need for useful classification system.

Children Act (1989)

This requires local agencies to cooperate to hold registers of children with disabilities. The definition written into the Children Act is widely regarded as dated and stigmatising and useless for any practical purposes.

A child is disabled if he is blind, deaf, or dumb or suffers from a mental disorder of any kind or is substantially and permanently handicapped by illness injury or congenital deformity or such other disability as may be prescribed.[4]

These words were based on the definition in the National Assistance Act (1948). They were retained partly to avoid any change of definition and therefore eligibility for benefits at the transition to adulthood, and partly because there was no national agreement on what a better definition should be. In particular the polarisation of proponents of medical and social models blocked progress.

Replacing the Children Act definition of disability

A recent interdisciplinary working group has suggested that a brief definition of childhood disability for Children Act purposes will include[5]:

● A statement about the age a child becomes an adult taking into account relevant legislation.

● The dimensions of disability which may be some version of the following list:

1. Locomotion
2. Fine motor
3. Personal care
4. Continence
5. Hearing
6. Vision
7. Communication
8. Learning
9. Behaviour and social integration
10. Physical health
11. Consciousness

● The threshold of severity for the purpose of registration.

● Indication that the disability is long lasting.

● Acknowledgement that objective measures of disability must be added to the effects of environment if loss of social role (disadvantage) is to be assessed.

Disability codes

In producing disability codes to define which children should be included on a health authority disability register, the writers should strike a balance between simplicity and complexity, between the imprecise and the unwieldy. Codes should have been produced from working discussion between health and social services and be academically grounded in the previous UK work. They should try to avoid defining disability by provision and try not to confuse current ability with prognosis. They should recognise that the predicaments of preschool children and adolescents demand different assessment procedures, different models of disability, and different ways of communication. Finally they should recognise that the families of disabled children and young disabled people themselves need a major role in defining their own disability.

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1 World Health Organisation. *International classification of impairments, disabilities and handicaps; a manual of classification relating to the consequences of disease.* Geneva: WHO, 1980.
2 Reiser R, Mason M. *Disability equality in the classroom: a human rights issue.* London: Disability Equality in Education, 1992. (Available from 78 Mildmay Grove, London N1 4PJ.)
3 Bone M, Meltzer H. *OPCS surveys of disability in Great Britain.* Report No 3. London: HMSO, 1989.
4 *The Children Act 1989. Guidance and regulations.* Volume 6. London: HMSO, 1991.
5 British Association for Community Child Health. *Disability in childhood, towards nationally useful definitions.* Discussion document. London: British Paediatric Association, 1994.