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).\(^1\)

\[
\begin{align*}
(A) & \quad \text{disease or disorder} \\
(B) & \quad \text{impairment} \\
(C) & \quad \text{disability} \\
(D) & \quad \text{handicap}
\end{align*}
\]

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: '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 diagrammatically shown below:

\[
\begin{align*}
(A) & \quad \text{disease or disorder} \\
(B) & \quad \text{impairment} \\
(C) & \quad \text{disability} \\
(D) & \quad \text{handicap} \\
(E) & \quad \text{disability} \\
(F) & \quad \text{social environment}
\end{align*}
\]

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 objec-
tive result of impairment, and by the disability rights move-
ment 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 disadvan-
tage 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 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 gradu-
ally improved. Disabled people still have a long list of
cognates 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 handi-
cap in a precise sense to describe the interaction between
a person with impairments and their unchanging envi-
ronment. However, the lay use of the word predates 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 handi-
cap continues to be used where the word disablement would do. To say ‘I am late for my handicap clinic’ is unhelpful in
two ways. Firstly the doctor’s task is almost certainly to
be focused on the contribution of the impairment to the dis-
ability. Secondly there is the assumption that all children
with impairments are automatically handicapped or hand-
icap 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 uncondi-
tionally, is confronting that assumption within himself or
herself. 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 con-
texts, or be sure to use it strictly in the way it was defined
within the ICIDH. In most clinical situations the word dis-
ability 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. 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.

Slight  Threshold  ‘Disabled’  Very severe

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. 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:

- 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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