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Factsheet – learning disabilities

Summary

- Learning disability is a label which is convenient for certain purposes, but people with learning disabilities are always people first.
- Different ways of defining and classifying learning disability are used, but all are open to some interpretation.
- There are few official statistics for numbers of people with a learning disability, and our knowledge is based on studies of prevalence.
- The causes of learning disabilities are not fully classified, but are mainly environmental or genetic factors, or chromosomal abnormalities.
- Support for people with learning disabilities has moved away from the medical model to a social model based on inclusion and integration.

Terminology

The term learning disability is a label. It is convenient in discussion and for planning services. But people who carry that label wear many others, such as friend, neighbour, relative, employee, colleague, fellow citizen. A label describes one aspect of a person, but does not capture the whole person.

Many people with learning disabilities prefer the term learning difficulties. This is the wording used by People First, an international advocacy organisation. In the UK, the Warnock Committee has suggested that learning difficulties should be used to refer to specific problems with

learning in children that might arise as a result of issues such as medical problems, emotional problems, and language impairments. Learning disabilities can be a useful term in that it indicates an overall impairment of intellect and function. Alternative expressions are also used, for example developmental disabilities and intellectual disabilities. There is at present no clear consensus. It is however widely accepted that whatever terms are used they should be clear, inclusive, and positive.

Definitions

The World Health Organisation defines learning disabilities as:

“a state of arrested or incomplete development of mind”.

Learning disability is a diagnosis, but it is not a disease, nor is it a physical or mental illness. Unlike the latter, so far as we know it is not treatable.

Internationally three criteria are regarded as requiring to be met before learning disabilities can be identified:

- Intellectual impairment
- Social or adaptive dysfunction
- Early onset

Intellectual impairment

IQ is one way of classifying learning disability:

- 50-70 mild learning disability
- 35-50 moderate learning disability
- 20-35 severe learning disability
- below 20 profound learning disability

However, there are problems with using IQ alone. Measurements can vary during a person's growth and development. Also, many of us have individual strengths and abilities which do not show up well in IQ tests. It is important to take into account as well the degree of social functioning and adaptation.

Social or adaptive dysfunction

Measuring the degree of impairment of social functioning can be difficult, too. Clearly some social impairments may be life threatening for the person, for example poor skills in eating and drinking, and in keeping warm and safe. Others, such as communication and social abilities, may be important to the individual's functioning in modern society. Also relevant are the extent of difficulties with understanding, learning and remembering new things, and in generalising any learning to new situations. Assessments of functioning should take into account the context within which the person is living, including personal and family circumstances, age, gender, culture and religion.

Early onset

The third criterion is that these impairments can be identified in the developmental period of life. They are present from childhood, not acquired later as a result of an accident, adult disease or illness, or dementia.

Other definitions

Within mental health legislation, the criminal justice system, and in relation to social security benefits, other terms and criteria may be used. It is important to recognise that these exist for specific legal purposes. This means that someone who fits the definition for one piece of legislation may not be covered by another.

Classifications

All levels of learning disability are points on a spectrum, and there are no clear dividing lines between them, or between people with mild learning disabilities and the general population. Some individuals with mild learning disabilities may even not be diagnosed because they function and adapt well socially. Most can communicate using spoken language, have reasonable skills, and given the chance can manage well with lower level but appropriate support. People with moderate to profound learning disabilities need a good deal more care and support. This frequently includes special help with communication, a higher degree of

risk assessment and protection, and more physical help with mobility, continence, and eating.

Numbers

Just as there is no consensus on terminology, there are no official statistics that tell us precisely how many people there are with learning disabilities in the UK. The information we have comes from a number of population studies which have focused on measuring prevalence rates. On a statistical basis 2.5% of the population should have learning disabilities. In fact, prevalence seems to be lower at about 1-2%, giving a total of between 602,000 and 1,204,000 in a UK population of 60.2 million. Partly this is because mortality is higher among people with more severe forms of learning disability than in the general population. Also in part it is due to not all cases of mild learning disabilities being identified. We can be more accurate about the numbers of people with moderate to profound learning disabilities because they almost all use services of some kind. They are thought to represent 0.35% of the total UK population, or about 210,700 people.

Causes

There are a number of reasons for finding out where possible the cause of a person's learning disabilities. One is that often individuals and their families want to know, and have a right to do so. There are also health factors. It is important to distinguish between learning disability and physical or mental health problems which may well be treatable. In addition, some forms of learning disability or syndromes are indicative of the likelihood of certain health problems occurring. Genetic counselling may also be needed for the family, and increasingly for people with learning disabilities themselves who plan to become parents.

Among people who have a mild learning disability, in about 50% of cases no cause has been identified. A number of environmental and genetic factors are thought to be significant, although clearly diagnosed genetic causes have been found in only 5% of people in this category. Higher rates in some social classes suggest that factors such as large families, overcrowding and poverty are important. Research increasingly points also to organic causes, such as exposure to alcohol and other toxins prior to birth, hypoxia and other problems at the time of birth, and some chromosomal abnormalities.

In people with severe or profound learning disabilities, chromosomal abnormalities cause about 40% of cases. Genetic factors account for 15%, prenatal and perinatal problems 10%, and postnatal issues a further 10%. Cases which are of unknown cause are fewer, but still high at around 25%.

Support

With the decline of the medical model of learning disabilities, the focus of support has shifted to health and social care, and to education. At the same time, the training of professionals and support staff in these areas is improving in content and structure. As a result people with learning disabilities are beginning to lead longer and better quality lives. Emphasis is now on inclusive approaches and community integration. Direct payments to enable individuals to purchase their own services, together with the growth of advocacy, are giving greater choice and control to people with learning disabilities in running their own lives. Developments in person-centred approaches and independent supported living are changing expectations. The combined effect is that new opportunities are being opened up for people with learning disabilities in areas such as employment, parenthood, lifelong learning and citizenship. Even so, much remains to be done.