



all about people

British Institute of Learning Disabilities,
Birmingham Research Park, 97 Vincent Drive,
Edgbaston, Birmingham, B15 2SQ
Telephone: 0121 415 6960 | Fax: 0121 415 6999
enquiries@bild.org.uk | www.bild.org.uk

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Ken Holland

Factsheet: Learning Disabilities

Summary

Individuals who have the label of a learning disability/difficulty can and should be described in many other ways including, friend, neighbour, relative, colleague, community member, partner, employee, parent. A label describes one aspect of a person, but does not capture the whole person.

Many people with learning disabilities prefer to use the term 'learning difficulty'. The two terms are interchangeable when used in the context of health and social care for adults.

In the UK, education services use the term 'learning difficulty' to also include people who have 'specific learning difficulties' (e.g., dyslexia), but who do not have a significant general impairment in intelligence.

Internationally three criteria are regarded as requiring to be met before a learning disability can be identified or diagnosed. These are:

- intellectual impairment (IQ)
- social or adaptive dysfunction combined with IQ
- early onset

The causes include genetic factors, infections before birth, brain injury or damage at birth, brain infections or brain damage after birth. However, for many who are diagnosed with having a general learning disability, the cause remains unknown.

There are four critical areas before, during and after birth where a learning disability could become present.

It is estimated that 1,198,000 people in England have a learning disability (2% of the general population).

Individuals are still excluded and marginalised and, continue to face discrimination in every aspect of their lives.

The promotion of person centred planning and support has made a significant contribution to the way people are supported, primarily as a result of individual's themselves saying what they want, how they want it and when they want it.

An individual budgets is money that is given to a person (or through a broker arrangement) to buy their own support packages and other things they need to meet their personal outcomes they have identified

in their support plans and/or person centred plans.

More people with learning disabilities are experiencing a better quality of life and for some their personal outcomes, dreams and aspirations are becoming a reality.

Terminology

It has been convenient for health, social care and education professionals to attach the label of learning disabilities (or difficulties) to children, young people and adults for the purposes of planning services, spending money and collecting data.

However, individuals who have this label can and should be described in many other ways including, friend, neighbour, relative, colleague, community member, partner, employee, parent. A label describes one aspect of a person, but does not capture the whole person.

Labels and terminology have changed over the last 200 years, from 'idiots' in the 1880's, through to 'mad', 'feeble minded' and 'imbecile' in the early 1900's. It wasn't until 1948, with the formation of the NHS that the term 'mental handicap' was first used and then only in 1959 when a distinction was made between 'mental handicap' and 'mental health'.

The more familiar terminology of learning disabilities started to be used in the early 1990's following the publication of the NHS and Community Care Act. Many people with learning disabilities prefer the term learning difficulties which was first used by People First, an independent advocacy organisation.

The distinction between disabilities and difficulties continues to be a subject for debate and although they are often interchangeable, it is broadly accepted that there is a difference between learning disabilities and learning difficulties as follows:

Learning disability – is a general term that refers to individuals who find it harder to learn, understand and communicate. Other terms that are used to describe an individual's situation include complex needs or high support needs.

Learning difficulty – is often used in educational settings and refers to individuals who have specific problems with learning as a result of either medical, emotional or language problems. Children and young people requiring special education needs (SEN) are often described as having a learning difficulty.

Neither label should prevent individuals from fulfilling their ambitions or dreams, but both are lifelong conditions that can have a significant impact on the person's life and that of their family. Many will require support to enable them to live as independently as possible and some will need 24 hour support.

Other terms that have been used include 'intellectual disabilities' and 'developmental disabilities', both of which are used internationally but not commonly used in the UK.

Definitions

Disability or Difficulty?

Many people with learning disabilities prefer to use the term 'learning difficulty'. The two terms are interchangeable when used in the context of health and social care for adults.

However, in UK education services, the term 'learning difficulty' also includes people who have 'specific learning difficulties' (e.g., dyslexia), but who do not have a significant general impairment in intelligence. However, the Special Educational Needs (SEN) codes of 'moderate learning difficulty', 'severe learning difficulty' and 'profound multiple learning difficulty' all refer to generalised learning difficulty of varying severity. Taken together they can be considered to be interchangeable with the adult health and social care term 'learning disability'. However, people with specific learning difficulties such as dyslexia do not have 'learning disabilities'.

The UK is the only country that uses the term 'learning disability' in this way. An increasing number of international organisations and countries (e.g., USA, Canada, Australia) use the term 'intellectual disability'. This term has also been used in Professor Mansell's report on services for people with severe and profound learning disabilities. The term 'intellectual disability' should be considered interchangeable with the UK term 'learning disability'.

1) Eric Emerson, Pauline Heslop, A working definition of Learning Disabilities. IHL, 2010

Valuing People

One of the most commonly used definitions in the UK is that contained in the Valuing People and Valuing People Now strategies. This states that a learning disability includes the presence of:

- a significantly reduced ability to understand new or complex information, to learn new skills (impaired intelligence), with;

- a reduced ability to cope independently (impaired social functioning);
- which started before adulthood, with a lasting effect on development.

World Organisation (WHO)

The WHO defines a learning disability as 'a state of arrested or incomplete development of the mind'.

The Education Act 1996 states that:

'a child has special educational needs if he or she has a learning difficulty which calls for special educational provision to be made for him or her.' It also says that 'a disability, which prevents or hinders them from making use of education facilities', amounts to a learning difficulty if it calls for special educational provision to be made.

Internationally three criteria are regarded as requiring to be met before a learning disability can be identified or diagnosed.

These are:

- intellectual impairment (IQ)
- social or adaptive dysfunction combined with IQ
- early onset

Intellectual Impairment

IQ classification is primarily used by health professionals to assess the presence and degree of learning disability. It should not be seen as the only method of identifying the presence of learning disability in an individual and the language associated with IQ scoring is now seen as outdated.

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

There are problems in using IQ, in that measurements can vary during a person's

growth and development but more importantly it doesn't capture the person's strengths and abilities very well. IQ is an important measurement, but only if it is carried out alongside other assessment and measurement including social functioning and adaptation.

Social or adaptive dysfunction

Again, assessing the social function of an individual alone can also present problems and must be seen in the wider context of a person's social environment, their support arrangements and general lifestyle.

Social functions include; communication, eating and drinking, keeping safe, personal care and recognising risks. When thinking about social functioning, it is important to remember that other factors that impact on these. For example; gender, religion, culture, age and ethnicity.

Recent Government policy has shifted the emphasis away from 'institutional' living – (residential, large supported living homes, NHS Campuses), towards a more inclusive approach, where individuals are living more independently in the community, being supported more flexibly, being encouraged to develop their skills and abilities and using individual budgets to facilitate this.

These are important steps towards inclusion, choice, control and independence and recognise that with the right person centred approaches, people with learning disabilities/ difficulties can be supported to use and develop their social functioning skills.

Early Onset

For the majority of individuals, the presence of a learning disability is from birth or during the early development period of life. Acquired learning disabilities as a result of a brain injury in later life may also result in a learning disability.

Causes

The causes include genetic factors, infections before birth, brain injury or damage at birth, brain infections or brain damage after birth. However, for many who are diagnosed with having a general learning disability, the cause remains unknown.

There are four critical areas where a learning disability could become present, these are:

Events before birth: Chromosomal conditions - Chromosomes make up the genetic blueprint of every individual and each of us usually has 46 chromosomes. Sometimes there can be an abnormality in an individual's chromosomes, and this may lead, in some cases, to learning disability.

Events before birth: Maternal factors - Some infections caught by the mother may be passed on to the unborn child, and may lead to learning disability. Other maternal factors include diet deficiencies and excessive consumption of alcohol.

Events before birth: Metabolic disorders - A person's metabolism controls the chemical changes which occur in the body. A common metabolic disorder is phenylketonuria, which is the lack of an enzyme which breaks down certain amino acids. This can be detected shortly after birth and controlled through diet. If it goes undetected then severe learning disabilities can result.

Events during birth: A learning disability may result if the baby's oxygen supply is interrupted for a significant length of time, or if the baby is born significantly premature and becomes ill shortly after birth.

Events after birth: Some childhood infections can affect the brain, causing learning disability; the most common of these are encephalitis and meningitis. Social and environmental factors, such as poor housing conditions, poor diet and health care, malnutrition, lack of stimulation and all forms of child abuse may lead to learning disability. Severe head injury, for example from a road accident, may result in learning disability.

2) Adapted from Enable Scotland, 2010

A child can also be born with a learning disability if certain genes are passed on by a parent. This is called inherited learning disability. The two most common causes of inherited learning disability are Fragile X syndrome and Down's syndrome. Fragile X syndrome and Down's syndrome are not learning disabilities, but people who have either condition are likely to have a learning disability too.

Numbers

It is still not possible to accurately state the prevalence or how many children and adults with learning disabilities there are in the UK.

For children, however, information collected by the DCFS suggests that (as of January 2006), 210,510 (2.6%) pupils were identified as having a primary special educational need (SEN)

associated with learning disabilities. However, this is likely to be an underestimate of the actual numbers.

It is estimated that 985,000 people in England have a learning disability (2% of the general population). This figure includes 828,000 adults (aged 18 or more). Of these adults, [we] estimated that 177,000 were known users of learning disability services in England (equivalent to 0.47% of the adult population).

It is predicted that that English population will rise from 50.9 million in 2007 to 53.5 million in 2017 (+5%) and 56.0 million in 2027 (+10% from 2007). If it is assumed that there will be no changes in the incidence and prevalence of learning disabilities, these changes in the general population will result in equivalent changes in the population of people with learning disabilities.

3) Eric Emerson, CeDR Research Report, May 2008

Support

The UK has seen a significant shift in the way people with learning disabilities should and could lead their lives, that embraces inclusion, being visible and part of the community, integrating into the wider mainstream provision, achieving health improvements and developing life skills for paid work, leisure and education.

Whilst this shift is supported by the vast majority of self advocates, family carers and professionals, the reality is that change has been slow and many people are still 'cared for' rather than 'supported with'. The result being that individuals are still excluded and marginalised and, continue to face discrimination in every aspect of their lives.

The promotion of person centred planning and support has also made a significant contribution to the way people are supported, primarily as a result of individuals themselves saying what they want, how they want it and when they want it.

Recent Government policy has promoted the use of individual budgets (sometimes referred to as personalisation, personal budgets, personalised support or self directed support). Individual budgets are part of the wider reform and changes to adult social care and were included in 'Putting People First', DH 2007, which outlined the government's vision of how personalisation of social care services will be introduced, allow people to have more choice and control over their own lives.

An individual budget is money that is given to a person (or through a broker arrangement) to buy their own support packages and other things they need to meet their personal outcomes they have identified in their support plans and/or person centred plans. People who have an individual budget have more control over their lives, decide on how the money is spent and when support is required, giving them more opportunities to participate in activities in the community at times that suit the individual. Before individuals get an individual budget, their needs and wishes will be assessed against a Resource Allocation System (RAS) which will determine what level of funding they will be entitled to.

Direct payments still exist and these also allow individuals to purchase their own services, but are generally not regarded as flexibly as having an individual budget.

Conclusion

More people with learning disabilities are experiencing a better quality of life and for some their personal outcomes, dreams and aspirations are becoming a reality. However, this remains a small percentage of the learning disability population and there are many areas where positive change has been negligible. For example paid work;

In England, only 6.4 per cent of people with moderate to severe learning disabilities known to adult social services are in paid employment (NHS Information Centre, Social Care and Mental Health Indicators from the National Indicator Set, England 2009-10, August 2010). This is far lower than the employment rate for all disabled people (47.4 per cent) and the working age population in England (77.3 per cent) (Labour Force Survey, quarter 2, 2009).

4) Office for Disability Issues, HM Government, 2010

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For more information and factsheets
about issues affecting people with
learning disabilities and family carers visit
our website www.bild.org.uk

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