# Unit 1 - The nature of learning disabilities

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# **Outline**

#### This Unit will:

- Explore why it is difficult to define learning disability because it means many things to many people.
- Identify that learning disability comprises significant sub-average intellectual functioning that coexists with below average social functioning and that this manifests itself before the age of 18.
- Identify that over time intellectual ability, legislative definitions, and social competence have all been used as indicative for establishing whether someone has learning disabilities.
- Confirm that 3-4 persons per 1,000 of the general population will have severe learning disabilities and 25-30 persons per 1,000 of the general population will have mild learning disabilities.
- Specifically identify the number of people with learning disabilities in Scotland.

# Introduction

The first part of this unit explores how we decide whether someone has learning disabilities, and to this extent it will help us to define what learning disability means. This is sometimes difficult because, as will be explained later in this unit, the term *learning disability* means many different things to many different people not only in Scotland but internationally and also between different health care professionals; other disciplines and service agencies. Following this we will explore some of the important issues surrounding the incidence and prevalence of learning disabilities and relate this particularly to Scotland, but it will be seen that this is an issue of universality. The final part of this unit will require you to read a number of narratives and undertake some essential learning activities. For those students interested in this field a number of optional activities will also be provided. The narratives originate from Callum (and his mum), Marie, Shona, Scott, Alan and Purdie. These names have been changed to respect confidentiality. These narratives are included to bring to this unit a sense of authenticity about the lives of people with learning disabilities and the experiences of their families in Scotland.

The review of services for people with learning disabilities, in Scotland - 'The same as you?' has identified that people with learning disabilities should:

- Be included, better understood and supported by the communities in which they live.
- Have information about their needs and the services available, so that they can take part, more fully, in decisions about them.
- Be at the centre of decision-making and have more control over their care.
- Have the same opportunities as others to get a job, develop as individuals, spend time with family and friends, enjoy life and get the extra support they need to do this.
- Be able to use local services wherever possible and special services if they need them. (Scottish Executive, 2000).

In comparison, the new White Paper in England - 'Valuing People' (DoH, 2001) is based upon the principles of rights, independence, choice and inclusion. Achieving these principles for people with learning disabilities and their families is, in part, dependent upon a knowledgeable and skilled work force. This first unit articulates a knowledge and value base that promotes people with learning disabilities as equal citizens and lays a foundation for the remainder of the units that follow. As specialist services for people with learning disabilities in Scotland become scarcer it will become increasingly important that people with learning disabilities do not become a forgotten

people, as has been the case in the past (see Unit 3). It is vitally important that those who work with this heterogeneous group of people truly understand the nature of learning disabilities.

# How do we decide whether someone has learning disabilities?

This next section considers the following criteria as way of deciding whether someone has learning disabilities;

- intellectual ability
- legislative definitions of learning disability
- social competence.

# Intellectual ability

Some would argue that intelligence is an obvious criterion upon which to judge whether someone has a learning disability. An immediate problem with this is being able to decide just what intelligence is. Within this unit we do not have the time or space to explore this issue in any great depth, but it is assumed that intelligence is something to do with the ability to solve problems and that this ability, or the absence of it, can be measured.

One way of measuring intelligence is by using intelligence tests. These tests have been used since the turn of the century; they serve the purpose of enabling a comparison of the intellectual ability of one individual to complete a range of standardised tests, against a large representative sample of the general population. The sample that an individual is compared with will be of similar chronological age. The score that an individual attains, on completion of tests, can then be converted into a percentile, providing information as to how this individual compares with others in the general population. Normally the percentile is converted to an intelligence quotient (IQ) that has been, and still is, used as the principle means for identifying learning disability. The intelligence test seeks to compare the mental age of an individual against their chronological age.

This is achieved by using the following formula:

$$\frac{\text{Mental age}}{\text{Chronological age}} \quad x \ 100 = IQ$$

In the formula, chronological age refers to the actual age of an individual and mental age refers to the developmental stage reached when compared to others of a similar age. If one divides the mental age by the chronological age one will derive a number and if this number is then multiplied by 100 one has arrived at a calculated IQ.

Clearly, given the nature of this formula, if it was continued to be used throughout an individual's life then IQ would progressively diminish, therefore

the formula is only of use until the chronological age of around 18 years. Given that intelligence is present (some would say not) in the population, and is evenly distributed, it is possible to measure how far an individual moves away from what constitutes 'normal'.

The World Health Organisation have organised the degree of disability (retardation) according to how far an individual moves away from the normal distribution of IQ for the general population, as has been discussed previously. Using this system, an individual who consistently scores 2 standard deviations below the 'norm' of an IQ test, that is – a measured IQ of less than 70, would be said to have learning disabilities. Those with an IQ of between 71 and 84 are said to be on the borderline of intellectual functioning whereas those within the range 50-69 are generally identified as having mild learning disabilities (mild mental retardation).

Moderate learning disabilities (moderate mental retardation) is identified when the IQ is in the range of 35-49. Severe learning disabilities (severe mental retardation) is reserved for people whose IQ is in the range of 20-34. Finally the term profound learning disabilities (profound mental retardation) is reserved for people whose complex additional disabilities, for example sensory, physical or behavioural, makes the measurement of IQ difficult.

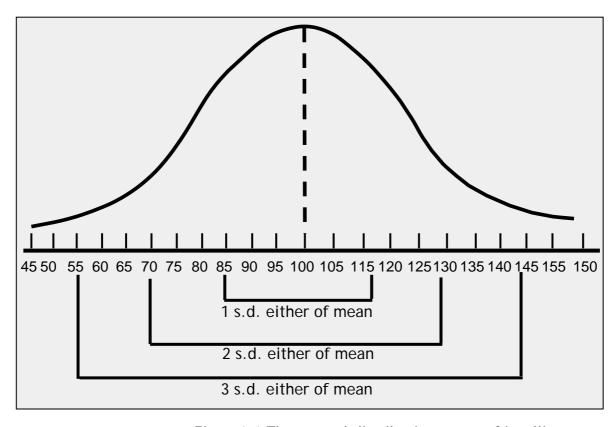


Figure 1.1 The normal distribution curve of intelligence

Intelligence tests were used extensively during the 1960s and 1970s; however, recognition by psychologists and others, of the many limitations of their use

has made them less popular today. These limitations include cultural bias, poor predictive ability, and a lack of relevance for the identification of learning disability. Despite the range of criticisms constructed against the use of intelligence tests, if used appropriately and by properly trained technicians then they do provide a relatively objective measure of the intellectual ability of an individual. In addition, if such a measure is used in conjunction with other criterion, such as social competence, this may be helpful in identifying whether an individual has learning disabilities.

## Legislative definitions of learning disability

It is the case that legislators, both within the UK and in other countries, have for centuries attempted to use the law to define learning disability and people conflating learning disabilities with mental illness may in part explain this. By this it is meant that the *clumping* together of two states of being has resulted in people with learning disabilities being the subject of much unnecessary legislation. This brief exploration only considers legislation this century, and in particular focuses upon mental health legislation. For a summary of the historical passage of legislation as it has affected people with learning disabilities see Unit 3.

The Mental Deficiency Act of 1913 said:

'Mental defectiveness means a condition of arrested or incomplete development of mind existing before the age of eighteen years, whether arising from inherent causes or induced by disease or injury'.

This Act followed the Radnor Commission of 1908, and introduced the compulsory certification of *defectives*. In a sense, this Act reflected the strong eugenics movement of the time; not surprisingly the Act required that 'defectives' be identified and then segregated from the rest of society. By 1959 terminology, and perhaps attitudes, had changed and the Mental Health Act of (1959) introduced the terms listed in Box 1.1.

**Subnormality** - a state of arrested or incomplete development of mind, not amounting to severe subnormality, which includes subnormality of intelligence, and is of such a nature or degree which requires, or is susceptible to, medical treatment or other special care or training of the patient.

Severe subnormality - a state of arrested or incomplete development of mind which includes subnormality of intelligence and is of such a nature or degree that the patient is incapable of living an independent life or guarding himself/herself against serious exploitation, or will be so incapable when of an age to do so.

Psychopathic disorder - a persistent disorder or disability of mind, whether or not including subnormality of intelligence, which results in abnormally aggressive or seriously irresponsible conduct, on the part of the patient and requires, or is susceptible to, medical treatment.

#### Box 1.1 Classifications of the 1959 Mental Health Act

This Act required local authorities to make day service and residential provisions for people with a *mental subnormality* and placed a new emphasis on the re-integration of this group of people into being part of the communities to which they belonged. However, this Act must be seen in context, and it should be remembered that it followed the implementation of the NHS Act (1948). The consequential medicalization of 'mental subnormality' following the NHS Act is clearly reflected in the Mental Health Act of 1959, and therefore its definitions reflected this. Note the strong emphasis, in the definitions, that was placed on treatment. In addition, the Act made extensive reference to the Responsible Medical Officer. It is at this point in the history of mental health legislation that the influence of medicine in defining the nature of learning disability exerted its greatest impact. As a result of continued social reform and pressure from lobby groups, mental health legislation was again reformed in 1983; the old Act of 1959 was replaced with the 1983/4 Mental Health (Scotland) Act; once again old terminology was changed and replaced with the terms shown in Box 1.2.

**Severe mental impairment -** a state of arrested or incomplete development of mind, which includes severe impairment of intelligence and social functioning and is associated with abnormally aggressive or seriously irresponsible conduct of the person concerned.

Mental impairment - a state of arrested or incomplete development of mind (not amounting to severe mental impairment) which includes significant impairment of intelligence and social functioning and is associated with abnormally aggressive or seriously irresponsible conduct on the part of the person concerned.

#### Box 1.2 Classifications of the 1984 Mental Health (Scotland) Act

It can be seen that the nature of these definitions excluded the large majority of people with learning disability; that is, unless learning disability (mental or severe mental impairment) coexisted with aggressive or seriously irresponsible behaviour, then they were not subject to this new piece of legislation. This Act represented a major shift in the perception of people with a learning disability in mental health legislation; for law separated the first time learning disability and mental illness.

# Social competence

The final criterion, in this chapter, that is used for identifying learning disability is that of social competence. Mittler (1979) has suggested that most countries have used criteria based on social competence that include the ability of an individual to adapt to the changing demands made by the society in which that individual lives. Of course this sounds relatively straightforward; that is, one simply identifies people who are socially incompetent, and who do not respond well to changing societal demands. Burton (1996) has said,

'Social competence concerns such areas as understanding and following social rules, adjusting social behaviour to the situation, social problem-solving, and understanding others. These are the areas where people typically fail independent living.' (Burton, 1996 p40)

On the basis of an individual performing significantly below what might be considered as *normal*, one presumably may say that they might have a learning disability. However, there are a number of problematic issues to consider in relation to the criterion of social competence. First, social incompetence is to be found in a wide cross-section of people; and not just those with a learning disability. Consider, for example, people with chronic mental health problems as well as non-conformists to societal norms.

Alternatively, there may be problems of communication, hearing and vision that could also be the cause of social incompetence, and may not necessarily involve a learning disability. Second, there is an issue here of expectation and the notion of a self-fulfilling prophecy. Assume, momentarily, that an individual is identified as having a learning disability, on the basis of measured social incompetence. Is it the case that this individual genuinely has learning disabilities, or is the social incompetence merely an artefact of the hospital setting in which this individual spent their formative years? Such a finding is not beyond the realms of credibility. It is only relatively recently in Scotland that the large learning disability hospitals have been closing. It is the case that thousands of people with a learning disability were segregated from society, and led very devalued life styles.

Opportunities for the development of social competence were few and far between even when opportunities arose; generally these were perverted attempts to create some kind of social reality within an institutional setting. There have been numerous studies undertaken on the effects of people who are deprived of normal environments. Dennis (1973) had found that institutionalised children were delayed in basic competencies such as sitting, standing and walking, and reported that they had no opportunity to practise these skills. It was also noted that with the additional lack of stimulation there was also significant delay in language acquisition, social skill development and emotional expression:

..... as babies they lay on their backs in their cribs throughout the first year and often for much of the second year.....Many objects available to most children did not exist.....There were no building blocks, no sandboxes, no scooters, no tricycles, no climbing apparatus, no swings. There were no pets or other animals of any sort.....they had had no opportunities to learn what these objects were. They never saw persons who lived in the outside world, except for rather rare visitors. (Dennis, 1973 pp22-23)

In short, the expectations of people in these environments were low, and therefore it is not unreasonable to assume that their ability to develop social competence in such environments was reduced. Despite the criticisms made in this section, the use of social competence as means for the identification of a learning disability remains a globally used criterion.

# Definitions of learning disability

Generally speaking in the UK the term learning disability is used, and this is accepted to mean:

'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) and which started before adulthood, with a lasting effect on development.' (DOH, 2001 p14)

Specifically in Scotland the term learning disability is used to describe:

'... those with a significant, lifelong condition that started before adulthood, that affects their development and which means they need help to understand information, learn skills and cope independently.' (Scottish Executive, 2000)

In the USA the American Association on Mental Retardation defined what we would call learning disability as:

'Mental retardation refers to substantial limitations in present functioning. It is characterised by significantly sub-average intellectual functioning, existing concurrently with related limitations in two or more of the following applicable adaptive skill areas: communication, self-care, home living, social skills, community use, self direction, health and safety, functional academics, leisure, and work. Mental retardation manifests itself before age 18.' (AAMR, 1997 p.5)

# A general discussion on terminology

It should be pointed out that the term 'learning disability' is relatively new; Emerson et al (2001) have suggested that its origins lie in a speech to Mencap by Stephen Dorrell, Minister for Health in England in 1991.

Its general usage in the UK is reserved for describing a group of people with significant developmental delay that results in arrested or incomplete achievement of the 'normal' milestones of human development. These milestones relate to intellectual, emotional, spiritual and social aspects of development. Significant delays in a number of these areas may lead to a person being described, defined or categorised as having learning disabilities. Despite wide usage of this term in the UK it should be remembered that it is not one that is used internationally (refer to the AAMR definition of learning disability [mental retardation]), nor is it a term that has been used for very long in the UK. Until recently the term 'mental handicap' was much more frequently used but was replaced, because it was felt that it portrayed negative imagery concerning people with disability. Interestingly a study by Nursey et al (1990) has demonstrated that parents and doctors had preferences in the words that they chose to use when referring to people with

learning disability. The study was conducted using a questionnaire and established that both parents and doctors preferred the term 'mental handicap' or 'learning difficulties'. However, the doctors were more inclined to accept the words dull, backward and developmentally delayed. In the USA (see above) the term 'mental retardation' is widely used for the classification of learning disability. This system is based upon the ICD-10 Classification of Mental and Behavioural Disorders, World Health Organisation 10th revision (1993). This uses the term 'mental retardation' to refer to:

'a condition of arrested or incomplete development of the mind, which is especially characterised by impairment skills manifested during the developmental period which contribute to the overall level of intelligence, i.e. cognitive, language, motor and social abilities.'

Interestingly the USA has recently been engaged in considerable debate about the use of the term mental retardation;

'As all of us have experienced, the term mental retardation has expanded from a diagnostic label embedded in both legislative and social norms to a pejorative, stigmatising term that is increasingly offensive to a large group of individuals.' (Schalock, 2001 p4)

Notwithstanding this, the American Association on Mental Retardation, 'noted that after two years of exploration for an alternative term they had not found one that meant the same thing, and on this basis they recommended that the term should not be replaced.' (Schalock, 2001 4)

You are asked to pay attention to terminology, as it is likely that America and other countries will adopt the term 'Intellectual Disability' in the future - remember people are sensitive to the labels or terms applied to them and some of these can be very hurtful.

It is becoming increasingly common for professional carers not to use the diagnostic labels and categories of description outlined earlier (Emerson et al, 2001). This is because they represent static measures that tell us nothing of the needs of each individual person; these needs will vary considerably between people, even if their measured IQ is an exact match with another.

In the field of learning disabilities, one of the problems in deciding which term to use is the possibility that the term may become used as a label that conjures up negative imagery. The use of labels for people with a learning disability has in the past served as a way of segregating this group from society at large.

Essential

Reader Activity 1.1

Spend ten minutes listing as many labels or terms that you have heard being used to refer to people with learning disabilities. Next compare your list with those in Box 1:3. These are all labels that I have heard people use when they refer to those with learning disabilities - do you think such labels assist in devaluing this group of people?

Imbecile Nutter
Cretin Moron
Spastic Benny
Subnormal Retard

Box 1.3 Terms used to describe people with a learning disability

# Incidence and prevalence of learning disability

Calculating the incidence of learning disability is extremely problematic. This is because there is no way of detecting the vast majority of infants who have a learning disability at birth. It is only the obvious manifestations of learning disability that can be detected at birth; for example Down's syndrome. In this example, the physical characteristics of Down's syndrome enable an early diagnosis and the ability to calculate incidence of this disorder. Where there is no obvious physical manifestation, one must wait for delay on a child's development in order to ascertain whether they have a learning disability. Therefore it is more common in learning disability to talk about the prevalence. Prevalence is concerned with an estimation of the number of people with a condition, disorder or disease as a proportion to the general population.

If one uses IQ as an indicator of learning disability then one is able to calculate that 2-3% of the population has an IQ below 70. This represents a large segment of society - given that a large number of people with such an estimated IQ never come into contact with any caring agency. It is more common to refer to the 'administrative prevalence'. Administrative prevalence refers to the number of people that are provided with some form of service from caring agencies. Historically, there has been a general consensus that the overall prevalence of moderate and severe learning disabilities was approximately 3-4 people per 1000 of the general population (see, for example Open University, 1987; DoH, 1992; Scottish Executive, 2001).

Such prevalence would appear to be universally common. For example, as long ago as 1985 Craft had suggested that international studies have identified a relatively constant prevalence for severe and moderate learning disability as 3.7 per 1000 population. The prevalence of mild learning disabilities is actually quite common; it has been estimated to be in the region of 20 persons per 1000 of the general population. In the UK it has been further calculated that of the 3-4 persons per 1000 population with a learning disability, approximately 30% will present with severe or profound learning

disabilities. Within this group it is not uncommon to find multiple disability that includes physical and, or, sensory impairments or disability as well as behavioural difficulties. It is this group of people that require life-long support in order for them to achieve and maintain a valued life style.

Drawing on more recent and extensive epidemiological data Emerson et al (2001), have reinforced the above estimations of prevalence rates for severe learning disabilities. They state it to be somewhere in the region of 3-4 persons per 1,000 of the general population. The prevalence rates for that section of the learning-disabled population referred to, as mild learning disabilities are much more diverse. It is estimated that this figure might lie between 25-30 people per 1,000 of the general population. Based on these estimates it can be assumed that there are some 230,000-350,000 persons with severe learning disabilities, and possibly 580,000-1,750,000 persons with mild learning disabilities. It is also known that there is a slight variation in ratio of males to females in both mild and severe learning disabilities; with males having slightly higher elevated prevalence rates. In Scotland there are an estimated 120,000 people with learning disabilities, however only 30,000 of these will have regular contact with local authorities or the National Health Service. Enable (2003) have suggested that 20 people out of every 1,000 have a mild or moderate learning disability and that 3-4 in every 1,000 have a profound or multiple disability. They also state that the number of people with learning disabilities has increased by 1.2 % a year over the last 35 years and that since 1965 the number of people with severe learning disabilities has increased by 50%.

**Optional** 

Reader Activity 1.2

Why do you think that the number of people with learning disabilities continues to grow, and why has the number of people with severe learning disabilities increased so dramatically and what implications might this have for future services?

This clearly represents a significant section of Scottish society and your local communities. Like other citizens they are entitled to access the resource of skilled professionals, who are able to meet their health and social care needs, when they are required. It will be noted that the incidence of learning disabilities has only been briefly outlined in this section. Research in this area is uncommon and with the exception of a few manifestations of learning disabilities, for example Down's syndrome (sees Unit 3), understanding incidence is fraught with difficulties of explanation because of an inability to identify learning disabilities at birth or even at a relatively young age. Earlier in this unit it was said that people use different criteria in identifying learning disabilities. This different use of terminology has implications for calculating incidence and, or, prevalence. It should be acknowledged that there is some controversy associated with calculation of incidence and prevalence. Some would argue that is unimportant and that the epidemiological study of learning disability creates labelling, and that this perpetuates inappropriate models of care that are developed outside mainstream services available for all of us. One problem, amongst many others, with this line of argument is that without careful epidemiological studies in this area, it is inherently difficult to know how best to target resources for those who may need them. It has long been complained that people with a learning disability are not afforded the same rights as other citizens. Careful measurement of incidence and prevalence provides one way of ensuring that people with special needs are provided with specialist resources when they are required.

# Introducing the narratives

The narratives used in this learning resource are intended to illustrate some aspects of five people's lives. These will explore various issues pertaining to these people who happen to have learning disabilities and recounts their experiences with health care professionals. Each of the units will direct you to at least one of the narratives and will ask you to undertake at least one essential reader activity.

Essential Reader Activity 1.3

You are asked to read all of the narratives of Marie, Shona, Scott, Alan and Purdie. Consider each of these and then form some small discussion groups and discuss the following questions. You may find it helpful to have someone to facilitate your discussion. You should allow at least one hour to read the narratives and for the discussion.

- ☐ Why do you think the doctor thought Marie was faking her epilepsy?
- ☐ Why does Shona say that people are frightened of people with learning disabilities? Are you frightened of people with learning disabilities if so why?
- ☐ What kind of information would you have given Scott?
- ☐ What would you do if you saw someone being rough with an individual as Alan reports?
- ☐ What do you think of Purdie's encounter with health care professionals?

# Conclusion

In this unit we have attempted to portray the complexities of learning disabilities. Many textbooks refer to 'people with learning disabilities' rather unproblematically as a homogenous group. This is simplistic and unhelpful; both for people with learning disabilities, their families and professional carers. Consider the narratives of Marie, Shona, Scott, Alan and Purdie, all might be said to have learning disabilities, but equally all are very different unique beings with their own very personal needs and aspirations. Also compare their narratives with that of the account provided about Callum from his mum. His very special needs make him very different from that of Marie, Shona, Scott, Alan and Purdie. Not with standing this people with learning disabilities, regardless of the impact of their learning disabilities, share a common humanity with the general population. Most people desire love, a sense of connection with others, to be safe, to learn, to lead a meaningful life, to be free from ridicule and harm, to be healthy and free from poverty, and people with learning disabilities, in this respect are no different. It is in the spirit of this common humanity that the rest of this text is presented. It is hoped that it will assist, in some small part, carers to bring about the inclusion of people with learning disabilities into their communities. It is for you as nurses to respect this and ensure that you offer nursing care to all people regardless of their difference and in this case we are referring to people with learning disabilities but nonetheless people who are the same as you!

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# Further reading

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# Resources

#### Scottish Executive

http://www.scotland.gov.uk - links to Scotland's policy's and documents for people with learning disabilities.

#### Centre on Human Policy

http://soeweb.syr.edu/thechp/ - John O'Brien home site lots on supported living/advocacy - useful mainly American links.

#### Department of Health - Learning Disabilities

http://www.doh.gov.uk/learningdisabilities/ - links to England's policy's and documents for people with learning disabilities.

#### **Enable**

http://www.enable.org.uk/ld/factsfigures.html - the Enable web site is a useful address for all kinds of information but here you can check out facts and figures for Scotland.

### National Electronic Library for Learning Disability

http://www.nelh.nhs.uk/nelld - National electronic library - excellent for the learning disability branch-useful reviews for example, supported employment.

#### British Institute for Learning Disabilities

http://www.bild.org.uk - source of good practice guidance; information and resource centre.

#### The Foundation for People with Learning Disabilities

http://www.learningdisablities.org.uk - works to improve the lives of people with learning disabilities through presenting views, research, and influencing policy.

#### Joseph Rowntree Foundation

http://www.jrf.org.uk - includes research, publications and social policy relating to learning disability.

#### King's Fund

http://www.kingsfund.org.uk - health promotion resource for the London area, research, publications and library.