Understanding learning disability

Introduction

People who have a family member who has learning disabilities and those working in close contact through learning disability services will have a reasonable understanding of the terminology used; others express real difficulties in understanding what type of person may be referred to when seeking to define the term and apply it to describe an incredibly diverse group. There is often confusion with other groups in society in particular people who have mental health disorders. The lack of clarity about what is meant by the term ‘learning disability’ can at times extend to those working in the field of practice, as those providing specialist services for people with learning disability are known to debate who can access their services. This emphasizes how difficult it can be to categorize and identify this group of people.

This chapter seeks to give some insight into the various service definitions while also sharing the individuality and skills of this marginalized group. The chapter also offers a brief overview of factors contributing to a person having learning disabilities and discusses some issues arising from different attitudes held in society that can perpetuate negative responses.

Individual perceptions can lead to assumptions being made about the people for whom we provide care. It is perhaps useful to reflect on your own thoughts and feelings when faced with minimal information about an individual requiring health care support. Take some time to reflect on your own thoughts and perceptions of the group of people who have learning disabilities and who they are by looking at the question posed in Text Box 1.
Text Box 1

What are your initial thoughts when told that a patient with learning disabilities has been admitted to your ward or arrives in your department?

Think about how you feel about that person and how that might affect the care you need to provide.

What is learning disability?

Definitions

Over a number of years terminology used to describe groups of people has changed, usually with a view to offering an acceptable and more positive image of marginalized groups. During 1992, learning disability was chosen in preference to the then used mental handicap, as this was thought to perpetuate negative thoughts and images of the people who make up this group. Learning disability conjures up various meanings to people and is sometimes incorrectly confused with mental ill health or types of learning difficulty such as dyslexia. The diversity of the group of people who have learning disability also gives rise to difficulties in offering a clear picture of who would be included. The definitions that follow are presented in an attempt to offer some clarity and understanding for health care professionals to appreciate the skills abilities and value of this group of people.

Learning disability is therefore used to describe a group of people whose ability with intellectual functioning is significantly lower than that of the general population. This, when coupled with impairments in social functioning, gives rise to a variety of difficulties for this group both in understanding information and recognizing when and how to gain support in all aspects of life.

Valuing People: A new strategy for learning disability for the 21st century was published in March 2001 (DOH, 2001c) and offers the following definition to guide services with the implementation of targets within the document.

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 lasting effect on development.

(DOH, 2001c)
Prior to this the World Health Organization, Classification of Diseases (ICD-10) (1992) using the term 'mental retardation' defined learning disability as a condition of arrested or incomplete development of the mind, which is especially characterized by impairment, during the developmental period, of skills which contribute to the overall level of intelligence, i.e., cognitive, language, motor and social abilities. The cognitive impairment must have occurred during the period of cognitive development, which is most often taken to mean before the age of 18.

Intelligence quotient (IQ) has historically acted as a guide to professionals in the field of learning disabilities when determining the individuals eligible to access services, those who were thought to have an IQ score below 70 would be eligible to receive specialist support from practitioners within the field of practice.

Valuing People (DOH, 2001c) discusses the relevance of a low intelligence quotient (IQ), and stresses that IQ of 70 or below cannot be used in isolation in determining the provision of specialist health and social care. Assessments of social functioning and communication skills should also be taken into account. It is worth noting that many people with learning disabilities will not have had a formal IQ test and as such no score would be available.

There has been some debate regarding the benefits of labelling. Gilman et al. (2000) suggests that in some cases labelling leads to dehumanization and disrespect and for others the label can create opportunity and open doors. For the purpose of service development it may well be beneficial to group these people together under the same definition or label to allow for improved future planning. This should not, however, be taken to mean that all people in the group will present themselves in the same way; people with learning disabilities are an incredibly diverse group of individuals with a broad range of skills who at various times throughout life will require varying levels of support from staff teams and family carers.

In terms of supporting mainstream health professionals to understand and appreciate the diversity, along with assistance to recognize the patient who may require additional support to access the full range of health care, it is useful to look at the broad categories of learning disability. As previously mentioned, the person’s IQ would have determined the level of service required. Although very few people with learning disability will have formal IQ tests linked to their diagnosis, the following descriptions can be used as a guide only to assist with general levels of functioning and skills a person has.

The World Health Organization (WHO, 1992) publication on the classification of mental and behaviour disorders (ICD-10) uses the term ‘mental retardation’ rather than learning disability and offers a brief description of the typical abilities. A person who will be described as having mild learning disability with an IQ score between 50 and 70 will be able to hold conversation, will
be independent in self care, may have basic or limited reading and writing skills and will be able to maintain social relationships and employment. People within this group may or may not require ongoing support. Many of the people in this group will live independently with any deficits in intellectual functioning going largely undetected. For this group primary care teams will provide much of their health care with little need for intervention from specialist teams.

Someone with moderate learning disability will have an IQ of around 35 to 50 and, although achieving a degree of independence, will probably require support in a number of areas to do so. People who make up the group of severe and profound learning disability as defined by the WHO ICD-10 classification (1992) will require greater levels of support from others to fulfil all of their daily living skills. Their IQ score will be below 35 and they are likely to have very limited or specialized communication skills and a high proportion may also have additional physical or mobility problems.

A person with mild or moderate learning disabilities will live independently and in many situations will be fully able to make decisions about how they live their lives. As a health worker you may need to be aware that the person with mild learning disabilities may require a little more time and consideration to reach understanding about health-related issues. Use of language the person understands and explaining why things need to be done will ensure consent or dissent is achieved from a fully informed basis.

People with moderate learning disabilities will also enjoy a level of independence despite requiring additional support in some aspects of life. Again the health worker will need to take time to fully explain procedures. This could be done with assistance from someone who the person trusts although this may not be necessary for all. It is worth noting that the majority of people who have learning disabilities will fall into the mild to moderate category.

People who have more severe or profound learning disabilities will require a greater level of support to access the wide range of health care. They are also much more likely to have other associated health needs such as epilepsy or respiratory problems because of their condition. People with severe or profound learning disabilities need to be listened to and will communicate their needs in a variety of ways and are often reliant on others for support in most or all aspects of life including identification of health-related problems.

Again the level of support required is dependent on the individual. As a health worker it is important that you listen not only to the person but you also listen to family, carers and friends of the person to ensure every aspect of care and their ability has been considered.

Despite the limitations in skills described above many people with learning disabilities are having increased opportunities to participate and contribute
skills within their community. Many people are gaining paid and meaningful employment that gives them a real sense of self worth. There are examples of employment opportunities within a whole range of services with people working in administrative and clerical posts, catering, acting, retail and many others. There are also several people with learning disabilities who are linked to sports with some excelling in their chosen area and competing in events like the Special Olympics. These opportunities for people offer great rewards for those involved and it is important that they increase.

**Prevalence rates**

Finding precise information on the number of people with learning disabilities in the population is difficult. *Valuing People* (DOH, 2001c) and *Once a Day* (DOH, 1999b) estimate approximately two per cent of the population will have learning disabilities. These figures can be explained as follows:

- Usually a general practitioner with a list of 2000 patients will have about 40 patients with learning disabilities, although there is considerable local variation.
- This ‘guesstimate’ includes children and elderly people.
- Of these 40 about eight will have severe/profound learning disabilities and the remainder will have mild/moderate disability, some of which will only have been evident during their school years. (DOH, 1999b)

- 210,000 people with severe and profound learning disabilities and
- 1.2 million people with mild/moderate learning disabilities live in England. (DOH, 2001c)

Whittaker (2004) explores the figures detailed in various Department of Health publications and points out that in studies mirrored nationally and internationally the number of people identified with the label learning disability who are known to services actually represents between 0.23% and 0.29% of the population. Whittaker (2004) goes on to question the need to seek out and apply labels to those who potentially cope independently of support from statutory services.

Although this group may be unidentified within specialist services we should not assume that as individuals they are accessing the full range of health care provision to which they are entitled. Many of the individuals will be living in the community with little or no support from family or friends. In many respects this group represents those who we assume have the necessary coping
HEALTH CARE PROVISION

skills and strategies to make meaningful decisions and choices regarding their self care. However, many within this group will lack the literacy skills required along with an understanding of what constitutes good health; as a result of this, their health will suffer. Primary care teams are most likely the only point of contact for people with learning disabilities who have not yet been identified and will need to ensure improved access to the NHS is available when needed.

Within the health economy there is much that can be done to empower people to improve their own health. If we can get things right for people who are known to have learning disabilities, health care provision will improve for all of us, including those who may fit the definition of learning disability in Valuing People (DOH, 2001c).

However we categorize or define individuals within society it should not detract from some of the basic human rights that we all expect. It is important therefore to remember that people who have learning disabilities are:

- FIRST AND FOREMOST PEOPLE WHO HAVE THE SAME RIGHTS AS ALL OF US.
- People who will at times require health services.
- People who require additional help in various aspects of their lives.
- People who are individual with differing needs.

Factors that can lead to a person having learning disability

For the purpose of this text the following causes of learning disability are not intended to be all encompassing. The intention is for the reader to gain a brief insight into some of the main reasons for learning disability occurring. When offering treatments or diagnosis of medical problems there may be some relevance or link to the cause of learning disability, however, it must be remembered that the individuals are first and foremost people who will inevitably suffer from illness and injury at various points in their lives. Very few of these difficulties can be attributed to the person’s learning disability, those that are, are often treatable complications that will require attention.

Social factors

Learning disability has no boundary and people from across all of the socio-economic groups can have a family member who has learning disability.
It is worth noting, however, that although prevalence of severe and profound learning disability is fairly uniformly distributed across the country and across socio-economic groups, mild to moderate learning disability does appear to have a link to poverty and rates are known to be higher in deprived and urban areas (DOH, 2001). There are a number of clear reasons for a person having learning disability although it is worth noting that in the majority of cases there is no clear identifiable cause of learning disability.

**Prenatal and peri-natal causes**

Prenatal factors are those affecting the development of the foetus before birth. The mother may have been exposed to infection or toxins such as drugs or alcohol. Viral infections such as Rubella (German Measles) in the early stages of pregnancy can cause severe learning disability with deafness, blindness and congenital heart defects. The severity of learning disability will usually be dependent on at what stage the infection occurred. Infection in the first three months of pregnancy represents the greatest risk to the unborn child. Since the programme of vaccination for rubella is now widespread across the UK very few cases of this type are found today.

Peri-natal factors are those caused at the time of birth or within the first 28 days of life (Watson, 2004). Birth trauma, lack of oxygen, or premature births can all result in the child developing learning disability.

**Postnatal factors**

A range of problems in childhood can result in developmental delay or learning disability as follows:

- Infections in childhood. Measles, meningitis and encephalitis can have an adverse affect on the development and sometimes causes learning disabilities.
- Accidental and non-accidental injuries are also known causes of learning disability.
- Toxic agents, use of lead in paints and other household materials were common factors although these are greatly reduced today.

**Genetic and chromosome disorders**

It is very difficult to state the proportion of people who have learning disability and the direct cause, but genetic and chromosome factors are estimated to be the
cause in some 26.5% of cases (Craft et al, 1985). Watson (2002) suggests this figure is likely to have increased with the emergence of research into genetics and influencing factors (Knight et al, 1999).

Although there are several genetic and chromosome abnormalities that contribute to people having a learning disability, this text does not seek to encompass all of these in any detail. A brief summary of the clinical features of Down’s syndrome and Fragile X syndrome is offered as these conditions represent the greatest number of genetic or chromosomal causes for a person having learning disabilities. For readers who would like to learn more, comprehensive lists of several genetic and chromosome disorders can be found in Mueller and Young (1998), Gilbert (2000) and Roy et al (2000). Additional information on learning disabilities and associated problems that could prove useful to the reader is also included in Roy et al (2000).

**Down’s syndrome**

Of all the chromosome abnormalities, Down’s syndrome is the one most commonly known and is thought to occur in approximately 1 in 650 live births (Mueller and Young, 1998).

Most adults with Down’s syndrome have a moderate learning disability with about 10% having low–normal intelligence and would not be classified as having a learning disability (Roy et al, 2000). Children with Down’s syndrome are likely to have speech and language delay and about 25% have features of attention deficit disorder.

There are a number of health-related issues for the person who has Down’s syndrome that may require ongoing monitoring or attention. The Down’s Syndrome Association (2004) have produced a useful schedule of health checks for adults with Down’s syndrome. Some of the clinical features that could benefit from regular screening and monitoring are shown in Table 1.1.

**Fragile X syndrome**

Fragile X is a genetic disorder first identified during the 1970s. The discovery of the Fragile X gene in 1991 has led to the development of reliable DNA tests enabling accurate diagnosis and can also identify possible carriers of the syndrome. The availability of accurate tests has identified Fragile X to be the most common inherited cause of learning disability.

The learning disability is usually mild to moderate and in some cases will not be apparent. Those with the syndrome have a certain set of characteristics. Roy et al (2000) describe people with Fragile X as having a long face with a large forehead, large prominent ears, a large lower jaw and high-arched palate. There is usually some degree of social impairment, with social anxiety and avoidance
of eye-to-eye contact. Over 90% of affected men have large testes, but this is not apparent until after puberty. Self-injury is a relatively common feature, biting of the hand in response to frustration, anxiety or excitement can occur quite frequently and repetitive behaviours like flapping or waving of the hands are not uncommon.

Speech and language development is delayed with dysfluent conversation, incomplete sentences and repetitive speech. Hyperactivity is a common feature among boys with Fragile X creating further challenges for the people around them. Clinical features that could benefit from regular screening and monitoring are shown in Table 1.2.

<table>
<thead>
<tr>
<th>Clinical Features</th>
<th>Monitoring</th>
</tr>
</thead>
<tbody>
<tr>
<td>Thyroid function disorders</td>
<td>Annual thyroid function test is recommended due to a high risk of dysfunction. Test and treat accordingly</td>
</tr>
<tr>
<td>Congenital heart defects</td>
<td>Regular monitoring as required</td>
</tr>
<tr>
<td>Respiratory tract infections</td>
<td>Treat infections as required. Look out for sleep apnoea</td>
</tr>
<tr>
<td>Obesity</td>
<td>Health promotion/dietary advice</td>
</tr>
<tr>
<td></td>
<td>Monitor weight at least annually</td>
</tr>
<tr>
<td>Skin conditions</td>
<td>Monitor and treat as appropriate</td>
</tr>
<tr>
<td>Increased risk of leukaemia</td>
<td>Monitor and treat as required</td>
</tr>
<tr>
<td>Hearing tests</td>
<td>Two yearly, also monitor for build up of ear wax due to narrow ear canals</td>
</tr>
<tr>
<td>Eye tests</td>
<td>Two yearly tests to check keratoconus and cataracts in adults</td>
</tr>
<tr>
<td>Muscular/skeletal. Atlantoaxial instability</td>
<td>May benefit from physiotherapy advice</td>
</tr>
<tr>
<td>Early onset of Alzheimer’s disease (post 40 years)</td>
<td>Regular review of skills and ability recommended from 30 years to ensure baseline skills information is available prior to any deterioration</td>
</tr>
</tbody>
</table>
### Table 1.2 Clinical features and monitoring for people who have Fragile X

<table>
<thead>
<tr>
<th>Clinical Features</th>
<th>Monitoring</th>
</tr>
</thead>
<tbody>
<tr>
<td>Visual and hearing impairment</td>
<td>Regular testing/treatment of recurring ear infection</td>
</tr>
<tr>
<td>Attention deficit/impaired social function/anxiety. Self-injury</td>
<td>Behavioural therapy and advice</td>
</tr>
<tr>
<td>Epilepsy 50% of males</td>
<td>Regular monitoring of medication and seizure patterns</td>
</tr>
<tr>
<td>Aortic dilation/mitral valve prolapse</td>
<td>Treat as necessary</td>
</tr>
<tr>
<td>Muscular-connective tissue dysplasia</td>
<td></td>
</tr>
<tr>
<td>Scoliosis</td>
<td></td>
</tr>
</tbody>
</table>

(Fragile X Society, 2005)

### Other conditions associated with learning disability

Causes of learning disability can also lead to other complications and or health conditions. Epilepsy is particularly prevalent in people with learning disability as are mental health disorders and autistic spectrum disorders. All of these conditions are also found in the general population but are found in increased numbers in the learning-disabled population. Differences in responses to treatments can also be noted and advice may be required to ensure appropriate action is taken.

#### Epilepsy

Approximately 30% of people with learning disabilities will also have epilepsy that continues into adulthood. This figure will increase with the severity of disability. People with learning disabilities are known to have poor control of seizures; this is thought to be due to the inherent brain damage. In addition, people with severe learning disabilities are not usually able to fully describe their experiences, and diagnosis may need to be made from information and descriptions of others. This makes it important to seek support and guidance to ensure all opportunities to improve seizure control are taken rather than accepting the situation.

The management of epilepsy in people with learning disabilities involves and requires the cooperative and collaborative working of the multi-disciplinary team, carers and users. Some areas of the country have introduced learning disability nurses with additional skills in epilepsy to support and manage issues arising from the dual diagnosis of learning disability and epilepsy (Doherty, 2003). These
nurses will offer a range of support and advice to people with learning disability, their carers and other health professionals.

**Cerebral palsy**

Up to one-third of people with learning disability will also have a physical disability. Cerebral palsy is a condition that affects development of muscle and nerves. Although it should indeed be noted that not all people who have cerebral palsy would also have learning disability or impaired intellectual function, they may well develop similar health-related difficulties.

Individuals who have cerebral palsy are at greater risk of developing postural difficulties, eating and swallowing problems along with chest infections. They may require assistance from a broad range of professionals to maintain mobility and good health.

**Mental health disorders**

Social isolation coupled with a lack of meaningful activities for some can contribute to depression and other mental health disorders. People with learning disabilities are often reliant on others, leaving them with having less control over their lives in comparison to others. This can result in unexpected or unwanted changes for the person, such as moving to a new and different environment, residing with unfamiliar people, and having different people providing direct care. This could in turn be the precipitating factor leading to mental ill health.

Roy *et al* (2000) report that the diagnosis of mental illness in people with learning disabilities can be problematic, especially if the diagnosis is one like schizophrenia, which depends on the communication of complex subjective experiences to the examining clinician. Language skills may be limited or absent, depending on the individual’s degree of disability. Doody *et al.* (1998) reported that people with learning disabilities are three times more likely to have schizophrenia than the general population. Despite this, access to mainstream mental health services for treatment remains particularly difficult. Various research papers suggest that this is due to the lack of communication between mainstream psychiatry services and learning disability psychiatry services (Moss *et al.*, 1996; Roy *et al.*, 1997; Hassiotis *et al.*, 2000).

It is also worth noting that within the field of learning disabilities there is high use of anti-psychotic medication. Interestingly, Emerson (2001) suggests that these drugs are most commonly prescribed for challenging behaviours rather than schizophrenia, despite poor indications of their effectiveness in treating challenging behaviours and the considerable evidence of harmful side-effects of this group of drugs.
Autism

About 70% of people with autism have a learning disability and the prevalence of autism increases with the severity of the learning disability. Briefly autism can be categorized by:

- having poor social skills, avoiding eye contact and physical interaction, being withdrawn
- being delayed with communication skills. Speech is often repetitive and, in some cases absent
- displaying repetitive behaviours such as twiddling objects and hand flapping
- preferring to maintain particular routines and a having real dislike of change in their lives
- developing a particular skill in one area that can become all consuming, e.g. mathematics, music or art.

Many people with learning disabilities will have some of the above characteristics making unfamiliar settings and situations very problematic and stressful for them. Difficulties can be anticipated for some individuals when requiring health care, and preparation will be crucial for routine screening procedures. This could involve visits to a department and/or preliminary work to familiarize the person with the relevant department or clinic. The specialist community learning disability team will be able to support this if required.

Attitudes

When providing health care to people it is important to identify need through conducting a full and holistic assessment. Nurses and other health professionals will always attempt to do this, however, many health providers report experiencing a degree of anxiety when dealing with people who fall outside what they know to be the norm. When faced with people who have the label ‘learning disabled’, health care teams often acknowledge difficulties with providing holistic assessment and care (Grossman et al, 2000). This can be attributed to a lack of awareness, preconceived perceptions along with their own fears and anxiety about this group of people. In addition the busy environments many health professionals find themselves in may contribute to difficulty in responding positively and giving the time required in undertaking a full and detailed assessment that involves the person in a meaningful way.

Government documents dating back to The Jay Report (1979) have indicated that people with learning disabilities should have the right to live a full life with
equal access to services as the rest of the population. The 2001 report, *Valuing People* (DOH 2001c) reiterates the same, with rights, choice, independence and inclusion featuring as a theme throughout the document. The document acknowledges that improving the lives of people with learning disabilities is a complex process, which requires a fundamental shift in attitude on the part of a range of public services and the wider local community. Generic or mainstream health professionals have yet to fully embrace this within their sphere of practice.

While (2004) suggests that the recent report, *Treat Me Right*, compiled by Mencap in 2004, provides a stark reminder that improvements in attitudes of public service employees is still required. The Mencap report (2004) details many health-related experiences. One reports a lady who, following surgery, was not communicating as she did prior to surgery. When this was discussed with staff they reported being unaware that the lady was able to speak! It would appear that a huge assumption was made in this case based on the label ‘learning disability’ with the resulting mistake that a cerebral bleed had gone undetected during emergency surgery and was only investigated days later when friends raised the question about her slow recovery and lack of speech. If a full account of the skills and abilities of this person had been undertaken and noted by all on admission, this would perhaps have been investigated much earlier. This account confirms the belief of While (2004) that low expectations of people with learning disability is often translated into unresponsive care, which leads to serious complications. While (2004) goes on to suggest that there is evidence to indicate that value judgements are made that frequently guide poor treatment decisions. While (2004) along with Mencap (2004) and others (Lennox and Dissens, 1999; McConkey and Truesdale, 2000) support the need for improvements in training and placement opportunities for mainstream health professionals, in particular opportunities to examine and improve attitudes, beliefs and values held towards people with learning disability is required.

Raising this topic recently with health professionals reveal some interesting anecdotes. On a positive note the majority of health professionals are supportive and would agree that people with learning disabilities should have access to the whole range of services. However, they acknowledge problems can arise when attempting to deal with individual cases. Some health professionals still hold the belief that people with learning disabilities should have access to specially trained doctors who only work with this group. Doctors who do specialize in this area clearly provide a valuable resource, but they traditionally focus on the mental health and neurological conditions affecting this group and as such are just as inclined to overlook the broad range of people’s physical illness.

Historically people with long-term mental health needs and/or learning disabilities were placed in hospitals and various institutions that were to provide for all their needs. In the case of many, their physical health needs were monitored
by hospital doctors who were often specializing in psychiatry rather than general practice. *Valuing People* (DOH, 2001c) makes this point stating that:

> Because mainstream health services have been slow in developing the capacity and skills to meet the needs of people with learning disabilities, some NHS specialist learning disability services have sought to provide all encompassing services on their own. As a result the wider NHS has failed to consider the needs of people with learning disabilities. This is the most important issue which the NHS needs to address for people with learning disabilities.

(DOH, 2001c)

It is now clear and widely accepted within the field of learning disabilities that to move forward and to address the issues and barriers highlighted in *Valuing People* (DOH, 2001c), a collaborative approach to developing high-quality health care is the way forward. A sharing of skills and knowledge will move us closer to a more accepting and understanding health service.

**Conclusion**

Learning disability is a condition used to describe an incredibly diverse group of people. Although it may be necessary to categorize people to plan for provision of any specialized services, it remains important to view the learning disabled as people first who have an important contribution to make in society. This chapter has explored the terminology along with some of the reasons why a person may have learning disability and the potential effects that can have on health. There are a number of medical conditions that although not unique to people with learning disabilities, do occur more frequently. These have been highlighted to improve reader awareness.

More importantly the chapter has touched on attitudes and assumptions held about individuals who have been given the label learning disabled, and the effects this can and frequently does have on the provision of appropriate health care. There is, amongst generic health professionals, acknowledgement of the need to have greater awareness of the diversity and needs of people who have learning disabilities. Working collaboratively to support and meet identified health needs is now seen as an important factor in the continued attempts at improving the overall health experience for this group.