There are no clear figures or a national system of recording learning disabilities but it is estimated that approximately 1,144,000 people in the UK have a learning disability of which 236,000 are children and 908,000 are adults (Public Health England 2013). It is crucial that, as health and social care professionals, we understand the nature of learning disabilities and are able to support people with learning disabilities to lead a normal life. Death by Indifference (Mencap 2007) bought to light the discrimination faced by people with learning disabilities their families and carers. It highlighted how deaths occurred due to widespread ignorance and indifference, rightly termed ‘institutional discrimination’ throughout the healthcare services. The report made a range of recommendations to ensure that people with a learning disability are treated fairly and respectfully: among these is that healthcare staff should receive learning disability training.

Learning objectives

After reading this CPD text, you should be able to:

• Understand the use of the term learning disabilities, pathways to diagnosis and causes.
• Begin to reflect on your own discriminatory behaviour towards people with learning disabilities.
• Begin to address the needs of people with learning disabilities through making reasonable adjustments to your own practice and services.

What is a learning disability?

Learning disability is defined by the Department of Health (2001) as a significant impairment of intelligence and social functioning both acquired before the age of 18. The terminology used to describe someone with a learning disability can be confusing and depends on which country you are in. In the UK, the term used is learning disability, in the US and in many other European countries the term intellectual disability has become popular. However people with learning disabilities themselves prefer the term learning difficulties. In general, we use the term learning difficulty in education to describe problems with learning that are not seen as reflecting a significant impairment in intelligence, such as dyslexia and dyspraxia. For the purpose of this article the term learning disability will be used.

Diagnosis

The term learning disability covers a range of individuals with varying abilities and needs. Understanding the degree of impairment can help to understand a person’s needs and the kind of support that is needed. A holistic approach to assessment is taken which involves assessing a person’s IQ, their ability to cope with daily living and what support they need to manage effectively. In the UK, we use the terms profound, severe, moderate and mild to describe gradations of impairment in people with learning disabilities but the divisions between the groups are not clear. The term multiple disabilities is also used to describe individuals with a combination of learning and other disabilities such as visual impairment.

In some instances a learning disability can be identified but others only become apparent as the child develops but does reach the expected milestones. Some learning disabilities may become apparent when children start school which in the UK is the September after the fourth birthday. Under the Children and Families Act 2014, social services have a duty to assess a child with disabilities and draw up a health and educational needs plan. It is important that learning disabilities are diagnosed as early as possible so that the child can receive the right support. Early signs can be difficult to spot here are some indications to look out for:

• At birth, a baby may struggle to suckle and digest their food.
• There may be delays in sitting, crawling or standing.
• There may be a delay in beginning to talk and to pronounce words and learn new ones
• The child may find it hard to remember things.
• They may have trouble understanding social rules.
• Some affected children have trouble solving problems
• They may also have difficulty in thinking logically or at least in a recognisable pattern of logic.

Causes

Causes of learning disabilities in general can be categorised into three areas: prior to birth, during birth and after the baby is born. However, sometimes the cause of a learning disability is not known. Pre-birth, a learning disability may be linked to genetic differences, for example Downs Syndrome and Fragile X, or to an infection such as Rubella. The mother’s behaviour may also be a factor: drinking alcohol in pregnancy may result in Foetal Alcohol Syndrome. During birth, a learning disability can result from a lack of oxygen for the baby in a variety of birth situations. Premature birth may also be a factor. After the baby is born, a learning disability can result from illness or from trauma to the brain. Deprivation of basic needs, through neglect, abuse and poor diet can also result in learning disabilities. Poverty is closely related to mild learning disability. Children from poorer families are more likely to have a learning disability. Some learning disabilities can result from multiple causes that arise due to a combination of factors before, during and after birth.
Autism and learning disabilities

Autism (also referred to as Autistic Spectrum Disorder or Conditions) is a developmental disability which begins in infancy or early adulthood. The term refers to a triad of impairments which includes:

- Difficulties with social interactions and relationships
- Difficulties with language and communication
- Difficulties with ways of thinking

Not all individuals with Autistic Spectrum Disorder have the same degree of symptoms. Some individuals with autism will also have a learning disability but not all individuals diagnosed with autism have a learning disability.

Overcoming our own prejudices towards people with learning disability

Mees (2013) argues that we need to understand that we do discriminate, judge and hold social representations of people with learning disabilities: ‘Valuing is an active cognitive process, which varies and is influenced by context’ (pg177). Making judgements and putting things into categories comes naturally to us and is natural cognitive behaviour. Therefore to be able to overcome discriminatory behaviour we need to understand how we judge others. Deep reflection is needed in order to bring to the surface the extent to which we discriminate and to understand the social representations that we hold of people with learning disabilities. A conscious decision needs to be made to create positive representations of people with learning disability and also to ensure that our behaviour does not devalue them. Further to this, our personal interactions with people with learning disability need to demonstrate value both through our attitudes and actions. The support that we offer should give people with learning disability the optimum power and involvement in decision making. Mees (2013) concludes that a number of wider changes in society are needed so that people with learning disabilities have the same rights as everyone else.

Health inequalities and learning disabilities

People with learning disabilities are 3 times as likely as people in the general population to have an avoidable death as a result of poor quality health care. The Confidential Inquiry Into Premature Deaths of People With Learning Disabilities (Heslop et al. 2013) recommended 18 improvements in services. These included identifying people with learning disabilities, the provision of reasonable adjustments, timely diagnosis and the avoidance of diagnostic overshadowing. Tuffrey-Wijne and Hollins (2014) suggest that identifying patients with a learning disability has proved to be problematic for a number of reasons, one of these being the fear of labelling people. They argue that to move forward, we should assess the needs of any individual and in doing so flag those who are particularly vulnerable such as people with learning disabilities, dementia, mental health problems, sensory and physical impairments. They propose that a senior clinical manager should be responsible for identifying these vulnerable people. Some examples of flagging are: the need for a carer/advocate present, needs extra time, needs easy read/pictorial explanations. They also suggest that this kind of patient data should be held in patient records as hospital passports are not carried reliably by patients.

Communicating with people with learning disabilities

When we communicate with someone with a learning disability, the principles of communication are the same as those of communicating with anyone else. Always assume that a person can communicate. Identify the person’s preferred learning and communication style, as we all have our own established preferences of how we give out information and how we receive information, such as visual, aural, verbal and tactile. In order to build an effective meaningful relationship with people with learning disabilities and to successfully communicate you need to use all the ways available to you to give and receive information. This is total communication approach uses a broad range of resources such as gestures, body language, signs, symbols, photographs, objects of reference, and electronic equipment as well as the spoken method.

A person’s communication needs should be documented and available to all those involved in their support and care. People with learning disabilities use a range of communicating tools such as Intensive Interaction, Communication Passports, Accessible Support Planning and Life Story work. It is important to follow the lead of the person you are communicating with and go at their pace. Here are some useful tips to follow:

The best way to communicate is face to face and one to one:

- Always identify yourself
- Use accessible language.
- Avoid long words and acronyms
- Find somewhere quiet to talk.
- Ask open questions - avoid questions that have a simple yes or no answer.
- Check with the person that you understand what they are saying by repeating back. “you have a pain in your knee? Is that right?”
- You can try drawing - even if your drawing is not the best it could be helpful.
- Using pictures and photos is a good way to communicate as well as facial expressions.

Behaviour is a way of communicating our needs. If we are not listened to, we can all get frustrated and angry. The same can apply to people with learning disabilities. The key to understanding challenging behaviour is to understand the need being expressed, and this can take time to establish. Take time to find clues that lead you to understand why someone is behaving in a particular way.

Further Reading

Below are useful websites that can further help you understand and work effectively with people with learning disabilities.

The GMC have a section on their website dedicated to Learning Disability. www.gmc-uk.org/learningdisabilities/17. apx

Foundation for People with Learning Disabilities: http://www.learningdisabilities.org.uk/
British Institute of Learning Disabilities: http://www.bild.org.uk/
http://www.intellectualdisability.info/ This website is dedicated to Health and Learning Disability Information.

Note that Learning Difficulties may appear differently, or be experienced, approached and discussed differently in minority ethnic groups. There are a number of resources and research projects which have explored this matter, and these can be found on the website of the Association for Real Change (www.arcuk.org.uk ) including the LaDDER Newsletters, and the research programme ‘Here to Stay’.

Equally salient, although more difficult to find resources of relevance, is the question of spirituality, faith/religion, and sexual orientation or sexuality in people with learning disabilities. These are matters that have a real impact on quality of life and should be considered carefully.

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