

CACHE Level 2

Certificate in the Principles of Working with Individuals with Learning Disabilities

PERSON-CENTRED VALUES

SIGNS OF ABUSE

EMPOWERMENT

ACTIVE PARTICIPATION

SOCIAL INCLUSION

LEGISLATION

RISK ASSESSMENT

Workbook 1

Section 1: Understand the context of supporting individuals with learning disabilities

This section of the workbook is designed to help you understand what is meant by the term 'learning disabilities' and how best to support individuals with learning disabilities. You will learn about how individuals with learning disabilities have been treated in the past and how this has affected how they are treated today. You will also learn about the major changes that have taken place in recent years, which have seen the ending of segregation as a public policy and an increasing emphasis on helping individuals with learning disabilities achieve equality, empowerment and independence.

What we mean by 'learning disability'

Please read the following as it will help you to answer question 1.

The term 'learning disability' is used when someone has more difficulty than most people in understanding new or complicated information or in learning new skills, and a reduced ability to cope independently in everyday life. There are different causes of learning disabilities, for example, brain damage sustained during birth or an inherited genetic condition, but all individuals will have developed their disabilities before reaching adulthood and will have them for life. The language used to describe individuals who have learning disabilities has often been hurtful and disrespectful towards them and is a very sensitive issue. Later in this module, we will look at the effect of the language used. It used to be common for individuals with learning disabilities to be described as mentally handicapped but this is no longer acceptable.

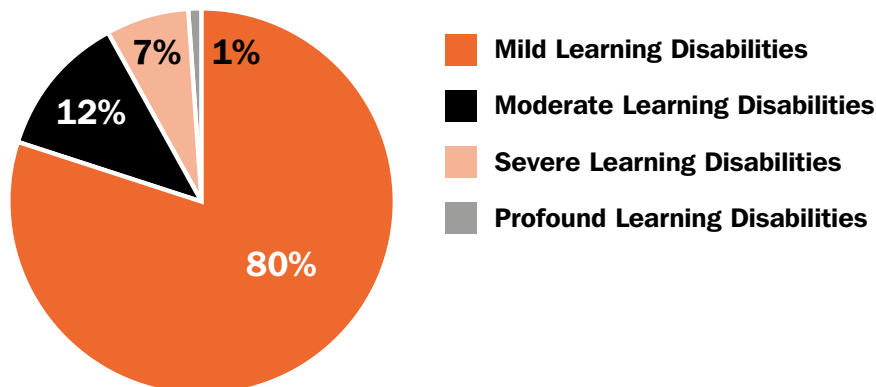
In England, around 1.2 million individuals are known to have learning disabilities but the term covers a very wide range or spectrum, ranging from those whose disability has comparatively little effect on their lives to those who need support and assistance with every aspect of their daily living.

Having the label 'learning disabilities' can be helpful in enabling individuals to obtain the health and social care services they need, and will provide individuals with protection from discrimination under the Equality Act 2010. Where individuals have not been identified as having learning disabilities, they can sometimes miss out on services which would benefit them.

To help ensure that individuals have the support they require, health and social care professionals break down the spectrum of learning disabilities into four groups.

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The spectrum of learning disabilities



Mild Learning Disabilities

Most individuals with learning disabilities (80%) fall into this category. Many go through life fairly independently and may only need help from social services or the NHS in the event of a crisis. They may benefit from additional help to access housing or employment but many will cope well enough without any help from social services.

Moderate Learning Disabilities

12% of individuals with learning disabilities are said to have a moderate level of disability. This means that they may need support with everyday tasks such as dealing with their money, paying bills and perhaps with personal hygiene. On the other hand, they are quite likely to be able to go out by themselves and may have a job. They will probably be able to communicate in words, although they may only have a limited range of words.

Severe Learning Disabilities

This is a smaller group (7%). Individuals are likely to need quite a lot of support with their personal care, in social activities and in communicating with people who they do not know.

Profound Learning Disabilities

Only 1% of individuals with learning disabilities are considered to fall into this category. They are likely to be very dependent on others for personal care and other essential needs. They will often not be able to communicate using words but may be able to do so by signing, electronic communication boards or by pointing (object referencing). Many will have additional health complications or impairments such as epilepsy, physical disabilities or sensory impairments.

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Why do individuals have learning disabilities?

Please read the following as it will help you to answer questions 2 and 3.

Learning disabilities can have a variety of causes but what everyone with learning disabilities has in common is that they acquired their disabilities at or prior to birth or in childhood.

Learning disabilities acquired before birth

An unborn child (foetus) can be affected by substances such as medicines, alcohol or drugs transferred from the bloodstream of the mother to the unborn child through the placenta. Damage to the unborn child can also be caused by exposure of the mother to radiation or toxic chemicals.

Another cause is a genetic condition inherited from either parent or caused by a faulty or missing gene. **Down's syndrome** is the most common genetic cause of a learning disability and perhaps the best known. Individuals with Down's syndrome have an extra copy of chromosome 21, which results in a distinctive appearance as well as learning disability. Some individuals who have Down's syndrome can be susceptible to heart defects and a range of other physical problems. The Down's Syndrome Association estimates that the condition affects 1 in every 1,000 babies born in the UK. Down's syndrome can be an inherited condition but more often occurs by chance.

Unlike Down's syndrome, individuals with **Fragile X syndrome** have the correct number of chromosomes but have a faulty gene on their X chromosome. Boys with Fragile X syndrome are likely to be more severely affected. The severity of the individual's learning disability will depend upon the degree of damage to the faulty gene. This is an inherited condition.

Other genetic conditions include:

Phenylketonuria (PKU)

This condition occurs because the individual's body is unable to break down phenylalanine, a substance which is found in protein. As a result of this, the level of phenylalanine builds up and although at first there are no harmful effects, if left untreated the child will develop severe learning disabilities. All babies born in the UK are now given a simple blood test to detect PKU. If given a special low-protein diet and an amino acid supplement from infancy, they should remain healthy and should not develop learning disabilities. PKU affects 1 in every 10,000 babies born in the UK and is the result of an inherited faulty gene.

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Prader-Willi syndrome (PWS)

PWS is a rare genetic disorder caused by a fault in the individual's chromosomes and happens purely by chance. There appear to be no specific causes and the disorder affects 1 in every 15,000 babies born in the UK. Individuals with PWS have learning disabilities, restricted growth, reduced muscle tone and often have a constant desire to eat which can lead to them becoming dangerously overweight.

Angelman syndrome

This is a genetic disorder affecting 1 in every 25,000 people. Children with Angelman syndrome will experience severe developmental delay, speech problems and coordination and balance problems.

Learning disabilities acquired during and after birth (within the first 28 days of life)

Although modern healthcare has reduced the risk of difficulties occurring during the birth of a child, sadly these dangers cannot be eliminated completely. Complications can occur at birth, such as when with a baby is in the breech (reverse) position. This and other difficulties can delay the period of giving birth, leading to the mother becoming exhausted and the baby becoming physically distressed, increasing the risk of trauma or harm to the baby.

Sometimes, the umbilical cord, which carries nutrients to the baby whilst in the womb, can become wrapped around the baby's neck before or during the process of birth; this can result in the baby being starved of oxygen. This is known as asphyxia and can result in damage to the baby's brain, causing learning disabilities.

Learning disabilities acquired during childhood

It may not always be clear whether or not a baby has a learning disability. This may only gradually become apparent as the child grows older and perhaps is slow to meet important stages in their development, known as 'milestones', for example, crawling, learning to walk or speaking.

Mild learning disabilities may be difficult to diagnose because it is often only when the child begins to mix and interact with others that it becomes clear that he or she is not as able as their peers.

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Sometimes, the child's mother feels instinctively that something is wrong, perhaps by comparing their progress with that of older siblings, but sometimes there may not be a formal diagnosis for several years.

Meningitis and other infections in early years can also contribute to the onset of learning disabilities, by causing damage to the brain, although strictly speaking this should be classified as Acquired Brain Injury (ABI) as opposed to learning disability.

Poor diet and lack of stimulation from parents and others can also lead to a failure to meet developmental targets and can contribute to learning disability.

There are also many individuals for whom the cause of their learning disability is never known. According to the British Institute for Learning Disabilities, this is the case for around 50% of individuals with mild learning disabilities. For individuals with severe or profound learning disabilities, the causes are usually clearer and the proportion for whom the cause is not known falls to a quarter (25%).

The impact on the family of having a member with a learning disability

Please read the following as it will help you to answer questions 4a and 4b.

Ultrasound scans and other checks during pregnancy may give an indication that the unborn child has a condition which could cause a learning disability and a test of the amniotic fluid which surrounds the baby in the womb, amniocentesis, may confirm that the baby has an inherited condition such as Down's syndrome. However, in many cases it only becomes clear that the baby has a disability after birth.

The reaction of parents and other members of the family to the news that a child has a learning disability can vary enormously. Parents will have their own hopes and dreams for their child and the diagnosis can cause feelings often associated with grief: shock, disbelief, anger and guilt. Others may deny that their child has a learning disability or may blame themselves.

Parents who suspect that their child has a learning disability may feel frustrated if this is not accepted by health professionals and may feel that they have to fight to ensure that they and their child obtain the help they need.

Having a family member with a learning disability also has an effect on other members of the family. Brothers and sisters may love their sibling but can sometimes resent the extra attention the child needs which will mean that they themselves may receive less attention or may need to take on more responsibilities. They may not understand why their brother or sister is unable to do certain things or behaves in a particular way. Sometimes, at school, they may also be the victim of bullying because they have a disabled sibling. Siblings may also mimic the behaviour of the individual with a learning disability, leading parents to believe that they also have problems.

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Grandparents may also have difficulty coming to terms with the child's learning disability, as they too will have had hopes for a different kind of future for their grandchild. They may also have grown up with a view that individuals with learning disabilities should lead separate lives with limited expectations, a view which is now changing in society as a whole but which can be difficult to adjust from. The view often expressed in the past, that couples should have their disabled baby 'put away' and try for another 'normal' child, can be hard to disregard for people brought up when these views were common.

Even if families remain positive, a diagnosis of learning disability does bring with it worries about the child's future care and support. Will he or she manage in mainstream school? Will they need any additional support at school? If they have additional healthcare needs, will the family have the support and equipment they need to look after them? What will happen during the transition from childhood to adulthood? Will the child ever be able to live independently? Will they be able to find and hold down a job? Finally, what will happen when the parents are no longer able to look after them?



Hannah's story

Hannah was our first baby and she seemed fine when she was born. As she grew though, we noticed that she wasn't really keeping up with children of the same age. She was late walking, late talking and late doing everything really. It was when she started school that it became obvious. She had difficulty with reading, communication and numbers. They told us she had moderate learning difficulties. The thing we worry about most is when we're not here any more to take care of her.

Different approaches to disability – the social and medical models

Please read the following as it will help you to answer questions 5a and 5b.

Models of disability are ways which have been put forward to help understand the nature of disability. Until recently, the most common view of disability was the **medical model**. In this model, the individual is regarded as disabled because of the inability of the individual's body to function correctly due to injury, illness or inherited or genetic characteristics. Under the medical model, the fact that an individual's body cannot function correctly is the main reason why the individual is 'disabled' and not able to take a full part in society.

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