Diploma - Level 3
Learning Disability Awareness
Unit 2 - The Causes of Learning Disability and the Effects on the Person and his/her Family

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2.1 Introduction

In this module, we shall consider how a person’s learning disability may be suspected or confirmed by the person, family members, and/or professionals. Specific conditions which may lead to learning disabilities are diagnosed by doctors and assessed by a range of professionals. This may lead to a diagnosis, but the cause(s) of a person’s learning disability may remain unclear or unknown. The effects of assessment, diagnosis, and uncertainty on the person and his or her family will be discussed.

People with learning disabilities have very individual combinations of strengths and difficulties which may impact on their day-to-day functioning. This module gives an overview of some of the ways in which people may need support and how their strengths can be built upon. These ideas are discussed in more depth later in the course.

The response of society in general to people with learning disabilities is very varied and ranges from highly positive to extremely negative. This module introduces these issues, and you will see that they are developed further as you work through the course.

2.2 Learning Outcomes

By the end of this module, the learner will be able to:

- Describe how some conditions leading to learning disability are diagnosed and assessed
- Describe specific examples of some conditions which may cause learning disability, such as Foetal Alcohol Syndrome
Discuss the effects on the family on discovering that their loved one has a learning disability and the effect of having specific causes diagnosed (or, conversely, the cause being unknown)

Outline the possible strengths and difficulties a person with learning disability may have in daily functioning

Explain the individual nature of the experience of having learning disabilities

Show awareness of society’s responses (both positive and negative) to learning disability in general.

2.3 What Do You Know Already?

Think about someone you know who has one or more family members with learning disability. This may be a family from your work or personal experience. In the box below, please write notes about:

- Whether the family knows the cause(s) of the learning disability
- How learning disability affects the daily functioning of the individual
- How the learning disability affects the family.
2.4 Assessment of Learning Disabilities

Some people with learning disabilities have one or more conditions known to be associated with learning disability. These conditions may be diagnosed by doctors:

- Before the person is born through pre-natal screening
- Soon after birth
- During childhood (often when investigations are carried out to determine why development is delayed)
- Later in the person’s life.

Others may have learning disabilities, but the cause of their learning disabilities may never be found even though tests and assessments may be carried out. This lack of certainty (and lack of a ‘label’) can have major implications for the person and their family.

Screening and Diagnostic Tests

These are the sorts of tests carried out by doctors in hospital alongside the antenatal (‘before birth’) checks carried out by midwives on pregnant women. Screening is the checking of apparently healthy people for conditions. Diagnosis means testing to find out which particular disorder(s) a person has.

Pre-natal tests are those carried out during the mother’s pregnancy. Please see the table below, which summarises why these may be done and gives examples:

<table>
<thead>
<tr>
<th>Type of test</th>
<th>People tested</th>
<th>Examples</th>
</tr>
</thead>
<tbody>
<tr>
<td>Routine screening tests</td>
<td>Offered to all pregnant women in the UK as part of the NHS Foetal Anomaly Screening Programme</td>
<td>This screening is to determine the likelihood that the baby has Down’s syndrome (also called Down syndrome). It is done by a detailed ultrasound scan and blood tests.</td>
</tr>
<tr>
<td>Additional tests</td>
<td>Offered to pregnant women considered to be at higher risk of carrying a child affected by a genetic disorder</td>
<td>Genetic disorders in the family may increase the likelihood that the baby is affected. Mothers from families affected by genetic conditions such as Fragile X may be offered additional tests.</td>
</tr>
<tr>
<td>Type of test</td>
<td>People tested</td>
<td>Examples</td>
</tr>
<tr>
<td>---------------------------------</td>
<td>------------------------------------------------------------------------------</td>
<td>-------------------------------------------------------------------------------------------------------------------------------------------</td>
</tr>
<tr>
<td>Extra antenatal checks</td>
<td>Offered to women who are considered to be at higher risk of carrying a baby who may have been harmed during the pregnancy</td>
<td>These check for infections in the mother, such as syphilis or HIV; nutritional deficiency in the mother; and exposure of the mother to harmful chemicals or radiation. Maternal conditions such as diabetes or complications of pregnancy can affect the baby, such as pre-eclampsia, which can develop into life-threatening eclampsia. Alcohol consumption by the mother leads to concerns that the child may develop Foetal Alcohol Spectrum Disorder (FASD).</td>
</tr>
</tbody>
</table>

Tests may be carried out on the child soon after the birth in the following circumstances:

- Prenatal tests suggested an increased risk that the baby may have one or more disorders
- The baby was premature or of low birth weight or seems unwell
- It was a particularly difficult birth, especially if the baby was starved of oxygen
- The appearance of the baby is significant. Some may have ‘dysmorphic features’, which means an appearance typical of a particular disorder. One of the most recognisable is the combination of features typically seen in individuals with Down’s syndrome (see picture below).
Tests for conditions causing learning disabilities may be carried out during infancy and childhood if a child has developmental delay or if he/she suffers a brain infection, head injury, neglect, or malnutrition, or if he/she has multiple difficulties suggesting an underlying genetic disorder. Other concerns, such as 'odd' responses to social situations or a loss of skills, can trigger tests and assessments. A small proportion of conditions causing learning disabilities are degenerative (the person becomes progressively more dependent on others) and may be life-limiting. We will consider the effects of such conditions on the person and family later in this course. People with learning disabilities have strengths too, which may be noted during assessments and used as a basis for enabling them to lead a full and happy life.

Assessment of Learning Disabilities
Assessment is a broader process than diagnostic testing and includes the person’s abilities as well as his or her difficulties.

Assessment of Intelligence
As noted in Module 1, below average intelligence (as measured by an IQ test score of 70 or less) is a defining feature of learning disability within the medical model. Some children who are thought to have a learning disability are given an IQ test which has been specifically adapted for their age. A common one used in Britain is the Wechsler Intelligence Scale for Children, now in its fourth edition (known as the WISC-IV).

Assessment of Development
Some people with learning disability will be identified in early childhood, as most will show some delay in their development. Usually children develop skills such as sitting, walking, and talking in a standard order and within a particular timescale. This is referred to as ‘meeting developmental milestones’. The milestones relate to the child’s abilities with regard to movement, speech and language, and social skills. For parents whose children meet developmental milestones, checking off the milestones can be a source of pride and joy, as illustrated by the chart below.

Chart from [http://www.plantoys.bg/userfiles/image/chart_en_930.jpg](http://www.plantoys.bg/userfiles/image/chart_en_930.jpg)
If a child is developing skills in the expected order but not within the expected timescale, he is developmentally delayed. This is often noted by the parents (and may cause dismay, anxiety, and deep sadness, as their child cannot join in/keep up with his peers, such as when playing at the park). Sometimes the GP or health visitor (who carries out developmental checks on young children) will be the first to notice developmental delay. Alternatively, it may be spotted by nursery or school staff.

However, developmental delay may not mean the child has a lasting problem; some who are slow to develop catch up in time and have no further problems. For this reason, some professionals are reluctant to refer children for more detailed assessment until they are about three to five years old, as this helps to avoid putting children who will turn out to have no problems through the process. This is understandable, but it can lead to frustration for parents and delayed identification (and therefore delayed help for) children who do have specific conditions.

Everyone with a learning disability is an individual, and those with the same diagnosis may show different patterns of development. This is illustrated in the table below, showing the development of three fictitious children on the autistic spectrum.

Child A has typical development throughout her childhood.

Child B has 'mild' autism but has additional physical disabilities often occurring with autism, and he shows significant developmental delay from infancy.

Child C shows typical development initially then delayed development later.

<table>
<thead>
<tr>
<th>Developmental milestone</th>
<th>Child A: Typical development</th>
<th>Child B: Developmental delay</th>
<th>Child C: Typical development initially, then delay</th>
</tr>
</thead>
<tbody>
<tr>
<td>Able to hold head steady</td>
<td>6 months</td>
<td>11 months</td>
<td>6 months</td>
</tr>
<tr>
<td>Able to sit unaided</td>
<td>9 months</td>
<td>15 months</td>
<td>8 months</td>
</tr>
<tr>
<td>Able to crawl</td>
<td>9 months</td>
<td>18 months</td>
<td>9 months</td>
</tr>
<tr>
<td>Able to stand holding on to furniture</td>
<td>12 months</td>
<td>22 months</td>
<td>11 months</td>
</tr>
<tr>
<td>Able to walk</td>
<td>15 months</td>
<td>2 years 3 months</td>
<td>16 months</td>
</tr>
<tr>
<td>Able to speak a few recognisable words</td>
<td>15 months</td>
<td>2 years</td>
<td>4 years</td>
</tr>
<tr>
<td>Able to speak short sentences</td>
<td>2 years</td>
<td>3 years</td>
<td>6 years</td>
</tr>
<tr>
<td>Able to run confidently</td>
<td>2 years</td>
<td>Still unsteady aged 10 years</td>
<td>Unable to run aged 10 years</td>
</tr>
<tr>
<td>Able to climb nursery equipment</td>
<td>2 years 6 months</td>
<td>Slow aged 10 years</td>
<td>Unable to climb 10 years</td>
</tr>
<tr>
<td>Joins in make believe play</td>
<td>3 years</td>
<td>6 years</td>
<td>Unable</td>
</tr>
<tr>
<td>Comforts others, takes turns, understands the need for rules</td>
<td>5 years</td>
<td>8 years</td>
<td>Unable</td>
</tr>
</tbody>
</table>

(Adapted from Sheridan, 1997)
**Developmental Delay Scenario**

You may have personal experience of parenting one or more children with developmental delay, or you may need to try and imagine this scenario. Please write notes in the box below about how you might feel on realising that your child cannot do the same things as his or her peers. Think about how you might feel when other parents proudly talk about their children’s accomplishments or how you might feel watching your child being overtaken by others much younger than yours. What might be your hopes and fears for his or her future?

**Assessment of Day-to-Day Functioning**

Many professionals are involved in the assessment of day-to-day functioning of people with learning disabilities. This may be part of your role or that of your colleagues. This will be covered in more detail in later modules, but in summary, this sort of assessment considers how independent a person is in terms of personal care; shopping; preparing and eating meals; mobility; and his or her ability to manage finances, relationships, and study or work. The person’s strengths as well as his or her difficulties are considered.

In later modules, we will consider the assessments people need of their physical and mental health in order to improve or maintain these.

Social assessment is also crucial, encompassing social relationships (including who cares for and supports the person), housing issues, finances, employment, gaining access to leisure activities, and so on. These issues will also be discussed further in later modules.
2.5 Specific Conditions Which Can Cause Learning Disability

There are a huge number of conditions which can cause learning disabilities, and many people have learning disabilities with no known cause. In this section, we will focus on two specific examples of conditions known to be associated with learning disability.

**Foetal Alcohol Spectrum Disorders (FASD)**

This is an umbrella term covering several disorders which can occur if a baby is exposed to alcohol before birth due to the mother drinking alcohol during pregnancy. Please refer to the diagram below (note that ‘foetal’ is the British spelling; ‘fetal’ is the spelling in other countries).

![Foetal Alcohol Spectrum Disorders Diagram](image)

As the word ‘spectrum’ suggests, Foetal Alcohol Spectrum Disorders range in severity to those causing mild difficulties to those leading to severe disability, including learning disability.

Alcohol drunk by the mother passes to the foetus through the placenta. The foetus has a liver which is not yet developed enough to filter out the toxins from the alcohol, and these toxins can kill the foetus’s brain cells or damage its nervous system at any stage of pregnancy. It is not known why some foetuses are more susceptible than others to such damage.
Possible physical effects of FASD include heart problems; damage to brain structure, bones, and kidneys; difficulties with vision and hearing; and specific facial characteristics. The diagram below shows the typical facial features of a young child with one FASD condition, called Foetal Alcohol Syndrome (FAS).

Craniofacial features associated with fetal alcohol syndrome

From a learning disability perspective, FASD can cause difficulties with attention, memory, abstract concepts (such as time and money), and problem solving. A person may show hyperactivity, be impulsive, and have difficulty with social skills. It is not surprising, therefore, that challenging behaviour is common when people are affected by FASD, and this has implications for family and school and for adult life. Early recognition of these issues and appropriate intervention can help a great deal, and this will be discussed in more detail later in the course.

There is a wealth of information about Foetal Alcohol Syndrome on the website of the National Organisation for Foetal Alcohol Syndrome UK (NOFAS-UK) at: www.nofas-uk.org

Action Point!

Please explore the NOFAS-UK website, including some of the videos featuring people talking about their experiences of Foetal Alcohol Syndrome.
**Down’s Syndrome**

Down’s syndrome (sometimes called Down syndrome) occurs when a person inherits an extra chromosome 21 (three instead of two). It is the most common genetic cause of learning disability, affecting about one in every one thousand babies who are born in the UK (BBC, 2012).

People with Down’s syndrome often have typical features, which include a rather flat profile, small ears, and sometimes a protruding tongue. Their muscle tone is often poor, with sight and hearing problems being common. About half develop heart defects, and some have gut problems. In later life, people have an increased risk of Alzheimer’s disease, and life expectancy is about 60 years.

Learning disability due to Down’s syndrome tends to range from moderate to severe. However, with the sort of support we will discuss later in this course, people with Down’s syndrome can lead fulfilling lives: some are independent in many ways, including being employed.

To learn more about Down’s syndrome, please visit the website of the Down’s Syndrome Association at: [www.downs-syndrome.org.uk](http://www.downs-syndrome.org.uk/)

There are numerous other conditions which can cause learning disability. There is more about some of these at [www.mencap.org.uk](http://www.mencap.org.uk).

**2.6 Day-to-Day Living with Learning Disability**

Broadly, the day-to-day effects of learning disability can be classified as follows:

**Effects on Perception, Understanding, Thinking, Learning, Imagination, and Decision Making**

There is a great deal of variation between individuals with each diagnosis. Some may have problems with all or most aspects of perceiving, making sense of the world, and being able to respond appropriately. Others will have a mix of average or above-average ability and difficulties. Some will have difficulty with some aspects and very great ability in others (such as those with high artistic or mathematical ability). Such abilities can lead to an extraordinary life for people who initially may appear very disabled.

Some people (such as many of those who are on the autistic spectrum) do not meet the criterion for learning disabled according to the medical definition, which requires a person to have an IQ of 70 or less. Nevertheless, many may be assumed to fall into this category if their behaviour (such as being mute and withdrawn) leads people to underestimate their capabilities. People with unusual behaviour or learning disabilities can be seriously disabled by the low expectations that others have of them. Conversely, a positive attitude by others can enable the person to achieve beyond others’ expectations, whatever her level of ability.
Specific cognitive (thinking) difficulties which people may have if they have learning disabilities include:

Short attention span, difficulty generalising from one situation to another, difficulty with abstract concepts such as time, problems with sequencing, memory difficulties, poor spatial awareness, oversensitivity to light, sound and/or touch.

All these can make learning difficult, especially in a busy school environment. Later modules describe how to support people with these difficulties.

**Practical Functioning**

The daily practicalities of living can be challenging for people with learning disabilities. Shopping, preparing meals and eating, washing, dressing, going to the toilet, getting out and about – all may need support from others. Some people will be totally dependent on others for all life’s practicalities; many others will need a lot of support for some aspects of daily living but less support for others. The individual nature of a person’s needs is a recurring theme of this course, and later modules look in detail at how people can be supported with regard to practical functioning.

**Communication and Behaviour**

Communication difficulties are common amongst people with learning disabilities, and they are often compounded by any physical disabilities which they may also have. Those with more severe disabilities may be reliant on communication aids. Non-verbal communication (gestures, facial expressions, posture) may be impaired. Difficulties with verbal communication include difficulty with the clarity of speech, intonation, fluency, pitch, and volume. Some people with learning disabilities may have difficulty recognising what is appropriate to communicate and what is not in specific situations.

Inevitably, those who have communication difficulties may not be able to make their needs and thoughts known. They may feel isolated and frustrated, and this may lead them to behave in ways which are perceived to be challenging by others. Communication and behaviour are therefore closely linked, and this course explains how people can be supported with regard to their communication and behaviour in Modules 3 and 4.

**Social Effects of Learning Disabilities**

From family and other relationships to managing finances and housing issues, there are many social aspects of daily life which may be particularly challenging for those with learning disabilities. There may be a great deal of support needed from family, friends, and professionals if a person is to achieve some level of independence in managing these aspects of his or her life. Accessing education, training, and employment may be especially difficult. Some people will always be dependent to some degree on the care and support of others to manage the social aspects of their lives. Later we will consider how best to support people with their social needs.
2.7 The Individual Nature of Learning Disability

Everyone is an individual, but sometimes people make the mistake of assuming that different people with the same diagnosis will be very similar. They are likely to share some similar traits, but they will also be very different from each other in other ways. The support given therefore needs to be tailored to suit each individual and be flexible to meet his or her changing needs over time.

Those working with learning disabled clients will have a very wide range of goals in accordance with the individual needs of their clients. Some will be supporting their clients towards independence, whilst others will be giving support to people who have profound and/or multiple disabilities who will always need a high level of support (there is more on this in Module 5). In all cases, a strengths-based approach will enable clients to reach their full potential. In other words, the strengths as well as the difficulties of each person need to be identified and built upon. Other ways to promote individuality when supporting those with learning disability include:

- Using a person-centred care approach (this means putting the person rather than the condition at the centre of care)
- Identifying and respecting the person’s individual attitudes, likes, choices, and values
- Supporting the inclusion, citizenship, and rights of clients (more on this later).

2.8 Effects of Learning Disability on the Family

Families with one or more members with learning disabilities are likely to be affected in many ways, both positively and negatively. Let’s first consider the potential family reactions to realising that their loved one has a learning disability (whether formally diagnosed with a disorder or not).

First, please see a mother’s reaction to her daughter Hannah’s diagnosis at:

Http://www.mencap.org.uk/node/11517

Families may react with shock and disbelief, confusion or anger. They may feel sorrow or relief to receive a diagnosis (which may take years). In the past, it was assumed that families went through a grieving process for the loss of the child they expected to have. Gates and Barr (2009) question this analogy with bereavement, as the child has not died and still needs to be cared for, which requires a process of adaptation from family members.

Parents may well be anxious about what the future holds for their family, about whether they can cope, and about the implications for finances, roles of family members, siblings, future children, and so on.
Families who do not receive a diagnosis may find this very difficult. Not only are they left in limbo about the cause of their loved one’s difficulties, they may find it more difficult to access the help they need and the benefits they may be entitled to, such as Disability Living Allowance. Some parents have an extremely difficult time, as their concerns are dismissed as over-anxiety. Some may be blamed for their child’s behaviour by those who do not understand that it is related to a learning disability.

Conversely, some families prefer not to have a diagnosis, which they fear may be a ‘label’ that leads to more harm than good for their child.

There is no doubt that families vary a great deal in the amount of support they receive, which impacts on their ability to not only cope but to thrive. Some families experience a huge amount of stress if inadequately supported, especially if also facing other disadvantages such as poverty. Other families receive wonderful support. Each family is unique, which makes the job of working with them varied and rewarding for the professionals involved.

Families often report that their relative with learning disabilities brings them joy and sometimes a perspective on life that they were missing before. The positive experiences of families should be acknowledged. There is a tendency for those who don’t have personal experience of learning disability to underestimate the huge benefits that individuals with learning disabilities bring to others.

2.9 Attitudes of Society to Learning Disability

Changes in Expectations

There have been major positive changes in attitudes to learning disabilities in recent years. Expectations are higher, and many people who would have been ‘written off’ as unable to do much at all are now being given the chance to lead full, productive lives.

Hate Crime

People with learning disabilities still face major prejudices though. Mencap report that 90 percent have experienced some form of harassment because of learning disability and other forms of hate crime. Hate crime is defined by the Crown Prosecution Service as:

‘…any criminal offence committed against a person or property that is motivated by hostility towards someone based on their disability, race, religion, gender identity or sexual orientation’ (CPS, 2012).

The crimes may take the form of attacks on the person or his/her property, threats (such as threatening text messages), verbal abuse, and bullying.
Many people are working to reduce hate crime and to support those affected, such as Mencap’s ‘Stand by me’ campaign and the national charity Stop Hate UK (www.stop hateuk.org).

Changes in Legislation

Legislation over recent years has shown significant changes in society’s attitude to learning disability. As noted in Module 1, laws and White Papers in recent times have enhanced the human rights of people with learning disabilities, along with their equal access, citizenship, and inclusion. These are positive changes which bode well for the future.

References


Personal Accounts

There are video and written accounts of hate crimes committed against people with learning disabilities on the Mencap website at: http://www.mencap.org.uk/campaigns/take-action/stand-me/real-life-stories
You may or may not want to view these, as by their nature they may be upsetting. This is an optional part of the course.