

## What is Learning Disability?

### Definitions

Learning Disability is a term used to describe the difficulties that some people have in learning things that society expects them to learn at certain stages in their lives.

Some people are born with certain conditions that restrict or reduce their ability to learn as quickly or as readily as others. Some people have a learning disability due to a genetic condition, an accident or illness during pregnancy, birth or in early childhood.

**Learning disability is not an illness; it is a permanent condition, although in some cases an accident or illness in early childhood may be associated with the condition. Some individuals are much more profoundly affected than others, these people may require help with most aspects of daily living, whereas those with mild disabilities can usually live with less support, but require some help with problem solving, social or emotional issues.**

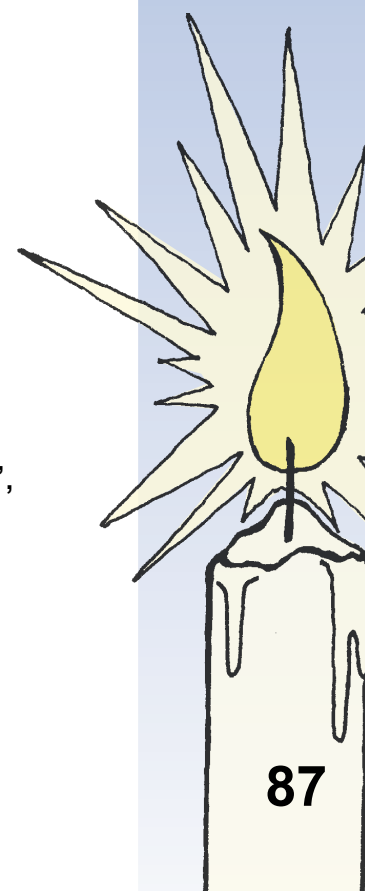
Like everyone else young people with learning disabilities are not all the same. They have different needs, come from all kinds of families and have varied lives.

Many people who have a learning disability also have physical and/or sensory conditions and/or associated health issues.

Autism is often included within the area of learning disability (especially in relation to CAMHS) but it is a different condition and those with Autism will need support that reflects this. Some of those at the higher level of the Autistic Spectrum Disorder may have average or even above average intellectual abilities, however people who have a learning disability may also be on the Autistic Spectrum.

The term learning disability is a relatively new one and in the past people who have a learning disability have had terms such as 'mentally deficient', 'mental handicap' and 'retarded'.

**(Scheerenberger 1983)**



Often, people still use the older terms and it is important to let them know that people with learning disabilities have chosen not to be referred to in these terms as they are oppressive and have negative connotations.

It is important to note that a **learning disability** is NOT the same as a **learning difficulty** although the two terms are often used interchangeably. This can be especially complex in educational settings where the term learning difficulty is used to cover a wide range of issues from dyslexia to profound learning disability. This resource is focused on those who have a learning disability.

**A learning disability is, “A significant intellectual impairment and deficits in social functioning or adaptive behaviour (basic everyday skills) which are present from childhood.” (www.learningdisabilities.org.uk)**

**A learning difficulty is: “a greater difficulty in learning than the majority of children of the same age.” An example of a learning difficulty is dyslexia. (www.learningdisabilities.org.uk)**

Some people with learning disabilities prefer to be known as having learning difficulties. They do not consider themselves learning disabled and it is important to respect this. Remember, individuals are people first and should be supported in a person centred way.

## **Families**

Families are sometimes given poor or ‘old fashioned’ views and opinions about learning disability when a child is born with a condition or diagnosed. Families can find it difficult to absorb information whilst they adjust to accepting that their baby has a learning disability. People often react and behave differently around people who have a learning disability, even when they are still babies who are no different to any other child. There has been increased coverage in the media. In 2006, BBC’s ‘Eastenders’ highlighted in a storyline about a baby born with Downs Syndrome, some of the possible reactions parents, family members and the wider community may have.

*“When a child has a disability, the mismatch between child and parental expectations and behaviour may be high; feelings of grief, denial and profound disappointment are often experienced by parents as they mourn the loss of the healthy baby they had hoped for”*

**(Singer and Powers 1993 p 26)**

Children and young people who are diagnosed and given the label 'learning disability' can face problems with interacting and becoming an active member of society. Families talk about constantly having to fight for their child to receive local services and participate in community activities.

It is important that families are given clear, accurate information about learning disability to be able to argue against the stereotypical views effectively. This is especially the case when working with people from BME communities where concepts can be 'lost in translation' (for example many languages do not have a word which effectively translates Autism). Links to sources of advice and support are included in this resource.

Learning disability is not an easy concept to understand and the definition and language used to describe it changes. This is due to increasing knowledge of conditions and the positive experiences of people living in and contributing to society that challenge theories and assumptions. Definitions tend to focus on significant limitations in both intelligence and adaptive functioning skills.

Some services require IQ testing and a person is considered to have a learning disability if their IQ score is less than 70. All local authorities should undertake a FACS (Fair Access to Care Services) assessment, this is a framework set down by the Department of Health that makes sure authorities are consistent on how decisions are made about whether people have access to services or not. The person is asked questions to establish if they need support with adaptive skill areas such as communication, self-care, daily living skills, community living, leisure, health and safety and self-direction. The person is assessed as needing help either critically, substantially, moderately or low. The assessment should consider the person's present situation and what could happen in the near future. As a result of the assessment, the person learns if they will be able to access services.

**Assessments that are led in this way can often lead to people only reporting on and viewing those who have a learning disability in negative terms and not recognising the individual's strengths, interests, skills and talents. It is important that these positive elements are included in a person's assessment. All people who have a learning disability should be seen as individuals first and those supporting them should not make assumptions or judgements about them based on stereotype.**

## **Impact of Diagnosis**

It may be easy to identify people with profound disabilities, and these people can have physical and/or sensory impairments as well as their learning disability. However, those who have a mild disability may be harder to identify. Although young people with conditions such as Downs Syndrome may have some common physical characteristics, many will not have any 'distinguishing' physical features. It is also true that the causes of having a learning disability are, in many cases, 'not known'. Having a diagnosis can ensure that the correct medical support is available but also lead to people making assumptions about life chances and limits of ability.

Some young people who have a learning disability may find it more difficult to understand new or complicated information. They may also find it harder than other young people to learn new skills - these may be practical things like tying shoelaces or social skills such as holding a conversation. This does not mean that a young person cannot learn, only that they will do so on a different time frame. Some young people may not speak and need to find other ways of communicating with those around them. Some need help with everyday things like getting dressed or making a cup of tea. Others will manage quite independently with much less assistance.

Tier One workers will be central in identifying changes in young people's usual behaviour. It is not their role to 'diagnose' the cause of the changes but they should be able to identify and refer on to other professionals the young person they have concerns about. Tier One workers should, as discussed elsewhere in this resource, also be promoting positive mental health and supporting recovery from mental ill health as part of their role.

## **Impact of Learning Disability on Mental Health**

People with learning disabilities are four times more likely to experience mental health problems (**Borthwick and Duffy, 1994/Emerson and Hatton, 2007**) This often goes overlooked and people's behaviour is attributed to their learning disability. People with learning disabilities experience the same kinds of mental health issues as the rest of the population but you may have to be more creative in recognising it. Any change in a young person's behaviour should be documented and not dismissed. Always ask for support and ideas from the family or other professionals, a young person's mental health is the responsibility of everyone involved in their care.

## **Rights and Choice**

Privacy is a basic human right and something we all value but can be denied to young people with learning disabilities. Parents and carers must think carefully about how a young person should be supported to have time alone in their own space and feel that they have control of this, their belongings and personal care routine.

This can be as simple as ensuring that a young person picks out their own toiletries and chooses what they wear that day and should filter through to bigger issues around relationships and support needs.

Remember! Giving choice is mentally challenging, especially when you are not used to it. Asking people to make choices when they are not used to it could affect their mental well-being.

## **Independence**

Striving for increased independence can be a difficult issue for the young person and their family. A young person with a learning disability may crave independence inside and outside of their home and become frustrated when this is blocked. Accepting independence is difficult for any family but be aware that some may not see it as a valid goal for their child to work towards. This may be due to their perception of the young person's disability, their health or it could be a cultural issue. It is important not to assume why a family behaves in the way it does but to ask and talk it through with them. This is important because of the repercussions it may have for the young person. They may experience some confusion from the different pressures on them.

**Staff and teachers may be encouraging the learning of new skills and to be as independent as possible whereas families might encourage them to be looked after and not complete tasks alone.** Reasons for this might be that a family might think if a young person shows too much independence, they may be refused any support or access to services. It may be that they believe that there is no need for a young person to learn skills as they will always have support from the family that for the young person to have to do things for themselves is a sign of their family neglecting them.

It is important to explain the concept of independence to the family. Independence is not a case of leaving the young person to cope alone or exposing them to unnecessary danger. It is an interdependence that allows them to build up their skills and have an increasing element of control over their lives.

## **How does learning disability link to mental health and BME communities?**

### **BME Communities**

Coming from a BME community and having a learning disability can lead to double or even triple discrimination. Although BME communities are dealt within a previous section there are some important issues to reinforce here.

Learning disability often does not translate well into other languages and so is not always recognised or understood by families from BME communities.

People from these communities often have significant problems accessing services due to:

- **Lack of knowledge and awareness** – communities are often unaware support is available and that services are increasingly translating material and identifying the need to include people from all communities.
- **Language barriers** – even though material may be translated this might not prevent language barriers including the use of jargon, abbreviations and initials when discussion matters. Indeed terms such as autism do not have a translated word in a number of languages. Also, be aware that some people are able to speak a language but not to read or write it.
- **Reluctance to get help** – many people from BME communities have had negative experiences when dealing with ‘the state’. Family members may often feel that no help is better than a negative experience for the young person.

- **Perceptions about the role of family** – in many cultures families are expected to deal with situation rather than rely on state interventions. Tier One staff should be able to support families to make decisions and feel involved.

The recently amended Services For All Families Handbook (2007) will be a useful resource for families increasing their awareness of available support and services. These can be downloaded, in a range of community languages, from the Mencap website.

[www.mencap.org.uk/html/ethnicity/servicesforall\\_ethnicity\\_languages.asp](http://www.mencap.org.uk/html/ethnicity/servicesforall_ethnicity_languages.asp)

## **Mental Health**

Count Us In (FPLD 2002) estimates that 40% of young people who have a learning disability experience mental health difficulties and often these people are unable to get support from services.

The risk factors that have been identified as ones likely to increase the risks of having a mental illness are common for people who have a learning disability, such as poor communication, social isolation and low self-esteem.

Young people with learning disabilities are often not identified as having mental health problems. Often individual's problems with their mental health are incorrectly attributed to their learning disability. Communication problems also do not aid the process of identifying mental health problems with these young people.

Those young people that are diagnosed as having a mental health problem as well as their learning disability are given a further label of 'dual diagnosis'. All mental health treatments must be holistic and need to consider possible therapies, medication treatments, counselling and social support.

The recently published A Mental Health Care Pathway for Children and Young People with Learning Disabilities: A resource pack for service planners and practitioners highlights the importance of a holistic approach. The pathway resource pack can be obtained for free from the Anna Freud Centre.

[www.annafreudcentre.org/ebpu/](http://www.annafreudcentre.org/ebpu/)



## Top Tips for Supporting a Person with a Learning Disability

### **Getting to know you**

Spending time with a young person when you meet them is key to establishing a good relationship with them. Make sure the child or young person has information about themselves that they can show to new professionals to help them explain what is important to them in a way they understand.

### **'Challenging Behaviour'**

Often people with learning disabilities are labelled as having challenging behaviour. However, the young person is using their behaviour to communicate with you, this might be because their previous attempts have failed with other professionals, perhaps that they are physically unwell or possibly that they are unhappy.

### **Friends and having fun**

Your friends shaped your identity and you chose to spend time with people who had similar interests as yourself. How can you help the people you support do this? Is there something the child or young person does during their week that they find really fun? Being young is all about trying new things and establishing your identity through your preferences and interests. Support a young person to find out what they really like to do and then support them to do it!

### **Taking Risks**

Staff members often protect children and young people from taking risks and making unusual decisions. Making mistakes is all part of growing up and it is important to enable a young person to do this with the security that they have someone to support them when they do.

### **Feelings**

A person with a learning disability has the same capacity for emotion as any other person. The difference is perhaps that a child or young person with a learning disability does not have the sophisticated way of communicating this that adults understand. You must try to understand what a young person is communicating and respect it as valid, as you would an adult or a person without a learning disability.

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**Interests**

Don't just talk about school! If a young person is not academically talented this means they immediately have to say something negative about themselves. Find out about interests where young people are experts and start off with that instead.

Recognising emotions and knowing how to handle them can be very difficult for some children and young people. It can be helpful to a young person and for you to get to know them better to identify your emotions.



### Exercise

Choose four emotions, for example, happy, sad, angry and anxious. Ask the young person to think about how they show other people how they feel. Encourage the young person to pull faces and demonstrate the body language and speech to show how they behave when they are feeling one of those emotions. Use a digital camera, a mirror or draw this to record it with the young person.

Ask the young person to give some examples of what makes them feel happy etc. Record these and talk about how they could happen more often or be avoided.

Now think about what the young person could or should do when they feel a particular way. For example, if they are happy about something, they should try to tell someone or make a record of it for their life story book. If they are sad they should know who they can approach to talk things through or get some support. They could also have individual ways of making themselves feel better, for example, looking at some photographs, having a soak in the bath or praying. Individual responses are key for when young people feel angry or anxious. It is a good idea to think about where a young person can go if possible, who they could talk to, what they could carry with them that might help reassure them. Identify these and record them to give the young person some ideas of coping mechanisms.

Tier One staff members will probably spend significant amounts of time with an individual and are well placed to recognise and record changes in behaviour and potential issues with their mental health.

**(For more details on Mental Health, refer to the Mental Health section of this resource)**



## Candle Case Study

**You** are a community support worker assisting a young Jewish man (Sasha) and his family.

Upon visiting you find Sasha unusually aggressive and he refuses to speak to you. This is the first time this has happened in the eight months you have been working with him.

Sasha's mum says he has been increasingly difficult to cope with having increasing verbally aggressive outbursts, reacting to small issues with swearing and minor incidents of self-harm (picking at his fingers to the point where they bleed – however, he says he doesn't like the sight of blood). He has been verbally aggressive to peers on the bus into school and was recently involved in a fight after he (according to the bus escort worker) spat at another person – he is not aggressive on the return journey.

His mum thinks this behaviour is part of his learning disability and is worried the behaviours will get worse as he gets older. She is certainly worried about being able to manage them as he grows physically.

**Q1. What questions could you ask Sasha and his mum?**

**Q2. Who else might you speak to?**

**Q3. What might you try and do about the behaviours?**

**Q4. Who else might need to become involved?**

**Q5. At what stage might you involve them?**

### Suggestions

**Q1. What questions could you ask Sasha and his mum?**

Has anything changed at home/within the family recently?

Have there been any recent changes to Sasha's routine?

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Has he been to see a GP about any medical illness or condition or have there been any changes to any prescribed medication?

Any other changes, particularly around school with staff, friends or routine?

**Q2. Who else might you speak to?**

School and teachers, GP, bus drivers and escorts, other family members, friends and peers at school. Think about a Circles Network for Sasha, help him to identify the different people in his life and then see if there are any gaps. He may feel like he does not have any friends so think about alternative ways to help him meet people who have the same interests as him.

**Q3. What might you try and do about the behaviours?**

The behaviours may be a form of communication that there is a problem, these need considering, however difficult. Work with Sasha to highlight the unacceptable nature of his current behaviour.

Provide alternative coping strategies/ways of communicating. Think about what he could do, especially on the bus to help him when he feels like he is going to lash out. This could be a simple thing like eating an apple or listening to his own music through headphones.

Contact other professionals to make sure they are all monitoring Sasha's behaviour and to see if they have any positive ideas about what helps Sasha. This could possibly include thinking about a CAMHS referral to arrange a review.

**Q4. Who else might need to become involved?**

All the professionals involved in Sasha's care, this might be the:

Social Worker

Health Workers

School – including school psychology, speech and language therapist

Other family members

Advocacy/befriending schemes

CAMHS professionals

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**Q5. At what stage might you involve them?**

This will probably depend on the success or otherwise of the initial attempts to support Sasha and his family. It can be hard to know when to intervene and you may find yourself not being supported by other professionals who do not consider it to be their role.

The Department of Health has a “*pathway*” that clearly states when services should be involved. If you contact a social worker or CAMHS worker they will be able to give you more information relevant to the individual case and advise you on the next steps.



**Candle Case Study**

**You** are classroom assistant for a group of 10 young people at a specialist learning disability school. The young people are aged 14, there are differing degrees of abilities within the group but they are very cohesive.

During a weekend, a popular member of the class dies suddenly and the group are very upset, two members in particular are acting differently – withdrawn and anxious.

One lady has multiple needs, no speech and communicates her choices with her eyes; the young person who died had been her close friend as well as supported her during lunch times.

You do not feel qualified to support the young people with their grief but have asked for additional support and have been told that is not possible at the moment.

**Q1. What could you do to support the young people emotionally?**

**Q2. Who else needs to be informed of the situation?**

Continued over

**Q3. Where might you be able to access resources and information?**

**Q4. What support might you require to undertake this work?**

**Q5. Who might be able to support you?**

### Suggestions

**Q1. What could you do to support the young people emotionally?**

Have a class or school assembly session remembering the person and having some kind of special symbol for example letting balloons or planting a tree that the children have chosen themselves.

Do some work on emotions in general. There are some good activities in the resource 'Muddles, Puddles and Sunshine' (**Winston's Wish, 2000**) that help children and young people look at the emotions and changes that a death brings in a sensitive but fun way.

Try getting some cameras or mirrors into the classroom and ask the young people to show different emotions, look at each others faces and talk about the reasons why they might feel one way and what could make them feel differently.

Make time to spend with the individuals who were most upset and reiterate the work on emotions.

Ensure everyone understands the reason why the person died – it might be that they are worrying that it might happen to them or people they are close to.

**Q2. Who else needs to be informed of the situation?**

Families/carers/residential support workers, social care staff, social workers, any CAMHS input the young people are receiving, school nurse, school psychology, educational welfare officers.

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**Q3. Where might you be able to access resources and information?**

Find resources in the library or on the internet about the loss of a person and about change and moving on – check out the recommended links and resources. Local counselling services may be able to assist you.

**Q4. What support might you require to undertake this work?**

Emotional support will be essential so try to raise issues with your team at meetings and use supervision to talk about your concerns. Access to the resources and information is also important, as well as time to plan, deliver and evaluate the work. Remember that you do not have to reinvent the wheel, there is work out there that will help you. Finding it takes time but try and build up a portfolio as you go of useful websites and resources. Have a look at the suggestions in the loss section in the mental health chapter of this resource.

**Q5. Who might be able to support you?**

Peers, senior teachers and those outside the school setting (many of those mentioned above should also offer support). Try to ensure your colleagues are working with you, it may be that some of them have been involved in work like this before. If not, it is possible that they will in the future so a good program for the school is very important.