

# Exploring learning disabilities: supporting belonging



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# Introduction and guidance

## Introduction and guidance

This free badged course, *Exploring learning disabilities: supporting belonging*, lasts 24 hours and is comprised of eight sessions. You can work through the course at your own pace, so if you have more time one week there is no problem with pushing on to complete a further study session. The eight sessions are linked to ensure a logical flow through the course. They are:

1. What is a learning disability?
2. History: different approaches to learning disability over time
3. Families
4. Education
5. Work and employment
6. Health and well-being
7. Relationships
8. Making belonging happen: rights and advocacy

In this course you will meet a number of people, pictured in Figure 1 below, and hear about their experiences.



**Figure 1** from left to right (top) Shaun, Dayo, Cian, Charlene (bottom) Terry, Phil, Clare Palmer, Elinor Palmer

Each session should take you around 3 hours. There are a number of activities throughout the course where you are asked to note down your response. A text box is provided for you to do this, however if you would prefer to record your answers in another way that is fine.

At the end of each session there is also a quiz to help you check your understanding. And, if you want to receive a formal statement of participation, at the end of Sessions 4 and 8 there is a quiz which you need to pass.

As you work through the course you may find you want to learn more. There are pointers at the end of each session to get you started. If you work in this field, or want to advocate more effectively, this course will give you some of the knowledge and the language to help you do that.

After completing this course, you should be able to:

- explain the term 'learning disability'
- describe different ways learning disabilities have been viewed over time
- reflect upon the impact that being labelled as having learning disabilities has on people and their families
- explain why it can be difficult for people with learning disabilities and their families to feel like they belong in society
- understand some of the barriers to people with learning disabilities and their families enjoying good lives and equal rights.

## Moving around the course

In the 'Summary' at the end of each session, you will find a link to the next session. If at any time you want to return to the start of the course, click on 'Full course description'. From here you can navigate to any part of the course.

It's also good practice, if you access a link from within a course page (including links to the quizzes), to open it in a new window or tab. That way you can easily return to where you've come from without having to use the back button on your browser.

The Open University would really appreciate a few minutes of your time to tell us about yourself and your expectations for the course before you begin, in our optional [start-of-course survey](#). Participation will be completely confidential and we will not pass on your details to others.

## What is a badged course?

While studying *Exploring learning disabilities: supporting belonging* you have the option to work towards gaining a digital badge.

Badged courses are a key part of The Open University's *mission to promote the educational well-being of the community*. The courses also provide another way of helping you to progress from informal to formal learning.

Completing a course will require about 24 hours of study time. However, you can study the course at any time and at a pace to suit you.



Badged courses are available on The Open University's [OpenLearn](#) website and do not cost anything to study. They differ from Open University courses because you do not receive support from a tutor, but you do get useful feedback from the interactive quizzes.

## What is a badge?

Digital badges are a new way of demonstrating online that you have gained a skill. Colleges and universities are working with employers and other organisations to develop open badges that help learners gain recognition for their skills, and support employers to identify the right candidate for a job.

Badges demonstrate your work and achievement on the course. You can share your achievement with friends, family and employers, and on social media. Badges are a great motivation, helping you to reach the end of the course. Gaining a badge often boosts confidence in the skills and abilities that underpin successful study. So, completing this course could encourage you to think about taking other courses.

## How to get a badge

Getting a badge is straightforward! Here's what you have to do:

- read each session of the course
- score 50% or more in the two badge quizzes in Session 4 and Session 8

For all the quizzes, you can have three attempts at most of the questions (for true or false type questions you usually only get one attempt). If you get the answer right first time you will get more marks than for a correct answer the second or third time. Therefore, please be aware that for the two badge quizzes it is possible to get all the questions right but not score 50% and be eligible for the badge on that attempt. If one of your answers is incorrect you will often receive helpful feedback and suggestions about how to work out the correct answer.

For the badge quizzes, if you're not successful in getting 50% the first time, after 24 hours you can attempt the whole quiz, and come back as many times as you like.

We hope that as many people as possible will gain an Open University badge – so you should see getting a badge as an opportunity to reflect on what you have learned rather than as a test.

If you need more guidance on getting a badge and what you can do with it, take a look at the [OpenLearn FAQs](#). When you gain your badge you will receive an email to notify you and you will be able to view and manage all your badges in [My OpenLearn](#) within 24 hours of completing the criteria to gain a badge.

Get started with [Session 1](#).

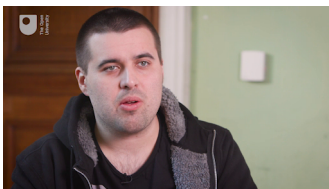


# Session 1: What is a learning disability?

## Introduction

Video content is not available in this format.

### Video 1



In this first session of the course you will consider the question: what is a learning disability? You will meet several people who have been labelled as having a learning disability, and you will be introduced to some definitions on the topic.

You will then find out how many people in the UK have a learning disability, and the sorts of places they live.

Finally, you will consider the rights that people with learning disabilities have, and whether it helps people to be labelled as having a learning disability.

In this session you will explore:

- what a learning disability is
- the different labels that have been used to describe people with learning disabilities and how people feel about those labels
- what life is like for people with more severe or profound learning disabilities
- some basic facts about the lives of people with learning disabilities
- people's rights.

The Open University would really appreciate a few minutes of your time to tell us about yourself and your expectations for the course before you begin, in our optional [start-of-course survey](#). Participation will be completely confidential and we will not pass on your details to others.



# 1 Being labelled

You will start by listening to a number of people with learning disabilities talking about their experiences of being labelled as having a learning disability.

## Activity 1 Labels

Allow about 10 minutes

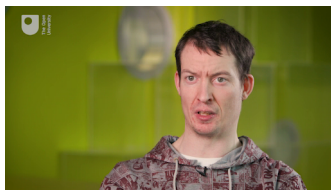
Watch this video clip of Shaun, Cian, Dayo and Phil talking about the labels that are used about them and other people with learning disabilities. How do people with a learning disability understand and make sense of these labels?

As you watch the film, make notes on:

1. the different labels that people mention (there are 18 of these);
2. whether they chose these labels, or if they were imposed by others;
3. how and why some labels become terms of abuse.

Video content is not available in this format.

## Video 2



1.2.3.

## Discussion

1. Did you find all these labels?  
Spastic, retard, imbecile, special needs, learning disability, mentally defective, mentally deficient, mentally challenged, autistic, weird, cheeky, trouble-maker, service-user, a learning-disabled person, mongoloid, learning difficulties, feeble-minded, disabled.
2. No one chose their label. Shaun quite liked 'cheeky' and 'trouble-maker', two labels which could apply to anyone, not just someone with a learning disability. The memory of his sister Bernie being called 'mongoloid' by the hospital was clearly upsetting for Phil.
3. Cian explained that when the label is first used it is often not meant to be rude. But over time, even quite innocent sounding labels like 'special needs' become terms of abuse.

This very first activity has introduced one of the most controversial issues in learning disabilities, that of the words to use. This course has chosen to use the term 'learning disability', as opposed to others like 'intellectual disability' or 'learning difficulties'. Some people believe that one of the reasons labels change so frequently is to escape the stigma that accompanies learning disability. But as Cian said, it hasn't worked!

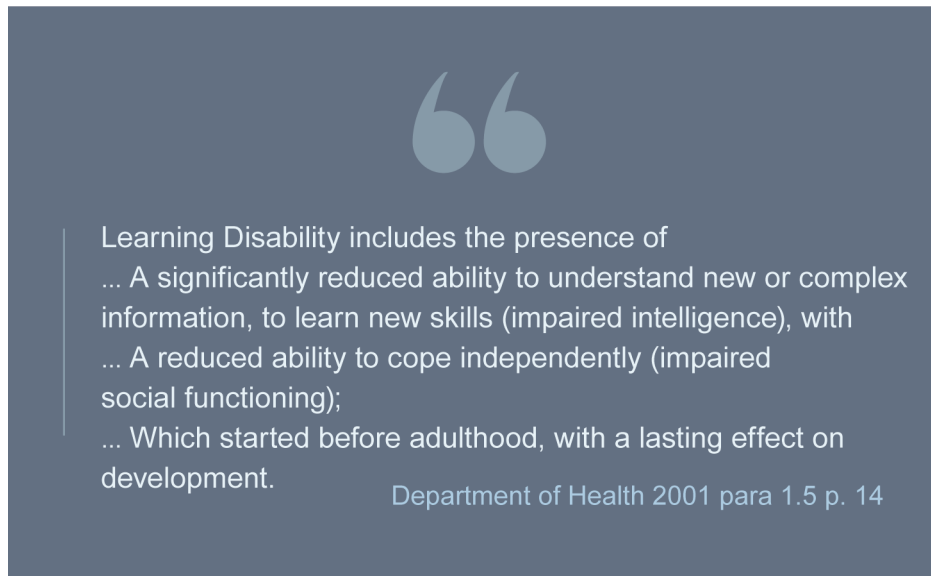
Later in this session you will look at the pros and cons of labelling. But first, some definitions.

## 2 What is a learning disability?

The previous section discussed how labels used about people with learning disabilities are controversial. But what exactly *is* a learning disability?

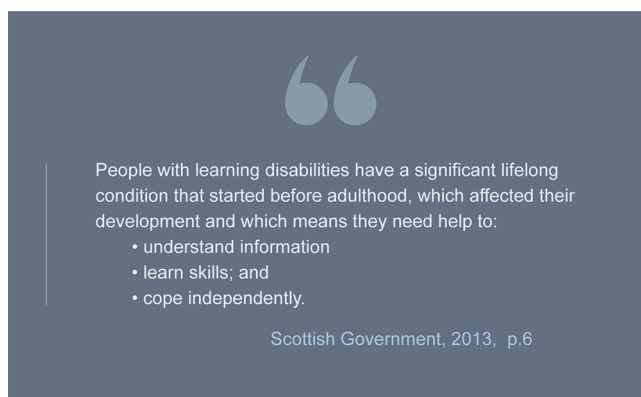
In this section you will be introduced to two recent definitions.

The definition in use in England (Figure 1) was adopted in 2001, from a White (Government) Paper called *Valuing People*.



**Figure 1** The English definition of a learning disability

The definition in the Scottish Government's *Keys to Life* strategy document (2013) is similar and a little clearer (Figure 2).



**Figure 2** The Scottish definition of a learning disability

You can see from both of these definitions that there are four key elements to identifying a learning disability:

- it is a lifelong condition
- you have more difficulty than others in understanding things
- you will struggle to learn new skills
- you may need some help to manage your life.



People sometimes believe that a learning disability applies to people who score less than 70 in intelligence tests, known as IQ. However, the strategy documents are unanimous – it is not enough just to measure intelligence. An assessment needs also to take account of social functioning and communication skills – in other words, how well people manage their lives.

## 2.1 Learning disability categories

The population of people with learning disabilities is sub-divided according to how severe their learning disability is.

There are four categories:

1. **Profound** – people whose IQ is estimated to be below 20, who often have additional complex health needs, and who may need help to eat, move around, communicate and do personal care.
2. **Severe** – people who may use a few words or gestures to communicate, are often able to look after their own personal care, but who need assistance with money, cooking, shopping, and possibly mobility.
3. **Moderate** – people who can communicate on a basic level, and can carry out everyday tasks with support.
4. **Mild** – people who speak fluently and need just a little support, perhaps with budgeting or accessing employment. The people you met in Video 2 would be classed as mildly learning disabled.

Next you will consider learning disability as a social condition.

## 3 Medical or social?

You might have come across debates about whether a learning disability is a medical or a social condition.

You already know from the definitions given in Section 2 that a learning disability is lifelong, meaning it cannot be cured. Some people are adamant that disability is socially created as society is organised for people who are not disabled. This argument is known as the social model of disability.

### Box 1 The social model of disability

The phrase 'social model of disability' was coined in the 1970s by UPIAS (Union of the Physically Impaired Against Segregation), a movement of physically disabled people, who said that people were not disabled by their bodies or minds, but by how they were treated in society. They said that society needed to reduce the barriers they experienced. You may be familiar with these ideas, as they have led to facilities like accessible toilets, hearing loops, ramps to help people in wheelchairs onto buses, etc.



**Figure 3** The social model of disability led to a number of positive changes for disabled people

UPIAS said the opposite of the social model is a 'medical model', which places the problem within the individual. The medical model suggests it is because people's bodies do not work well that they are excluded – therefore it is their own fault.

Like the physical disabilities UPIAS was talking about, learning disability is also not a medical condition. There is no 'cure', no drug that will alleviate it. If it can be cured it is not,

by definition, a learning disability. Where people with learning disabilities do need medical help, it is frequently because of other, associated conditions that they might have, like epilepsy.

You could argue that people with learning disabilities are disabled by society. If people cannot communicate in speech, if they cannot read or write, they will certainly find it hard to take part on equal terms with people who can – in competing for a job, for example.

### Activity 2 A learning disability friendly society?

Allow about 5 minutes

Click the link below to answer the poll on what you consider important in order for a society to be friendlier to people with a learning disability.

[Link: A learning disability friendly society?](#)

Once you have submitted your choice you can then see how others have voted.

Much of what services and supporters do is based on ideas associated with the social model; to try to create an environment which will minimise the impact of the learning disability. It won't go away, but lots can be done to make life enjoyable. It is this you will consider next.

## 4 Listening to people who do not use words to communicate

Three of the people you met in Video 2 in Section 1 – Shaun, Cian and Dayo – would be labelled as having mild or moderate learning disabilities. They can lead their lives with some support from their families, friends or paid staff. They also have views on what they want their lives to be like, and can share them.

However, people with profound or severe learning disabilities cannot communicate as directly. Finding out what support they need to enjoy life requires imagination and empathy. Watch this short clip of Ronke, a support worker, who explains how she found out that her 'client' loves to invite members of her family to Sunday lunch.

Video content is not available in this format.

### Video 3



Were you impressed with the way Ronke pieced together little bits of information to find a way to make her 'client' happy?

In the next activity, you will try using your own imagination and empathy to work out how to 'listen' to people who do not use words to communicate.

### Activity 3 Listening to people who do not use words

Allow about 10 minutes

Video 4 shows short clips of people who do not use words to communicate.

As you watch it, note down three things you could try to help you find out what they enjoy doing.

Video content is not available in this format.

#### Video 4



*Provide your answer...*

#### Answer

Here are some ways you could find out more about the people you met in the video.

1. Spend time with them at different times of the day.
2. Try lots of different experiences and observe how they respond.
3. Find out from people who know them well what they enjoy doing and who they like to spend time with.

Clare, whose daughter Elinor appeared near the end of Video 4, explains how she found out what Elinor likes doing.

Elinor loves doing lots of things – music, gigs, swimming, food. How do we know? By her behaviour and responses. By the sensual delight she takes in the feel of water in the swimming pool. By her smiles when songs she likes are played. She gives us clear messages.

In the next section you will think more about how the lives of people with severe or profound learning disabilities can be improved.

## 4.1 Improving the lives of people with severe or



## profound learning disabilities

What other things might help to improve the lives of people who have higher support needs?

### Activity 4 Changing society?

Allow about 10 minutes

Let's go back to the question about changing society, this time with a focus on people with severe or profound learning disabilities.

1. Watch Video 5, about Marvin, narrated by his mum. Then consider what changes to society could improve Marvin's quality of life by answering the poll below.

Video content is not available in this format.

#### Video 5



Click the link below to vote for the change you think would most improve Marvin's quality of life

[Link: Changing society?](#)

Once you have submitted your choice you can then see how others have voted.

In this section you have thought about supporting people who are not able to tell us what would make their lives full and enjoyable, and how the social model of disability might apply to them.

In the next section you will learn how many people have a learning disability and where they live.



## 5 How many people have a learning disability?

This might sound like an easy question, but there are no easy answers because the definition is very broad. It includes Shaun and Cian, who need only a little help to live a very full life, as well as people with severe or profound learning disabilities who need 24-hour care.

There have been attempts to count the number of people with a learning disability in the countries of the UK. However, it is important to note that the four nations capture this data independently and use different definitions of the population, which makes it difficult to compare figures. Some recent figures for England are given in Table 1.

**Table 1 Learning disability statistics in England**

	England (2015 figures)
<b>No. of people with a learning disability</b>	1,087,100
<b>People supported long term by social services</b>	124,000 (11% of the estimated adult learning-disabled population)
<b>Number of people identified by GPs</b>	252,446 (23% of the estimated adult learning-disabled population)
<b>Children with Special Educational Needs</b>	70,065

(Public Health England, 2016)

These figures, however, are unsatisfactory for a number of reasons, not all of them immediately evident. For example, the figures are not collected regularly and there is no universal system for labelling adults. Also, the figures are not broken down into the four sub-categories you looked at in Section 2.1, meaning the data is quite vague. Nevertheless, they do reveal some important points.

1. There are a lot of people with a learning disability...
2. ...only a minority of whom are supported by social care services – people like Dora, Bhavin and Elinor whom you saw in Video 4.
3. The majority of adults with a learning disability are more like Shaun, Cian, Charlene and Terry – people who get by with little or no help from social services.
4. GPs identify more people than are supported by social services.

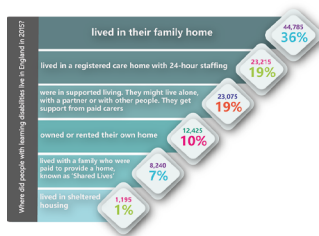
Many people who were labelled as having special needs at school do not continue to have the label learning disability as adults. Chris Hatton, a senior academic, argues in his blog that as money has got tighter with austerity policies since 2010, fewer people are being labelled as having a learning disability – because there are no services to support them (2019).

## 6 Where do people with learning disabilities live?

In answering this question, you will not consider children as most live with their families.

In 2015, there were 124,000 people receiving long-term support from a local authority in England because they had a learning disability. We know where they live because the state has some responsibility for them. However, we don't know about the others – no one is counting them.

Because they need support, many of the 124,000 people live in locations where they can access help, from family or from paid staff.



**Figure 4** Where people with learning disabilities live in England

You may have noticed that these figures only add up to 92%, which means we do not have details for where the remaining 8% of people live.

In the next activity you will compare the data from England with that of Wales.

### Activity 5 Where do people with learning disabilities live in Wales?

Allow about 10 minutes

These are the figures for where people with learning disabilities lived in Wales, in 2017/2018:

- Own home: 16%
- With parents or family: 53%
- A foster home: 2%
- Lodgings / supported living: 21%

(We do not have details for where the remaining 8% of people live.)

What are some of the most striking differences between England and Wales?

*Provide your answer...*

### Discussion

You may have noticed that many more people with learning disabilities live with their families in Wales than in England (61% compared with 36%). The Wales figures do not explicitly show anybody living in a registered care home, which is another big

difference compared to England. It is possible that they are included in the lodgings / supported living categories, and some of the small numbers living in health service accommodation, but it is not possible to be sure. This highlights the difficulties in comparing data across different countries.

In this section you have considered how many people have a learning disability, and the sorts of places where they might live as adults.

Given the relatively small number of people with a learning disability supported by local councils (remember there are over one million people living with a learning disability in England), you might wonder why bother to use labels at all. It is this that you will come to next.

## 7 To label or not to label

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You have seen how difficult it is to decide how many people have a learning disability as the definition is broad and imprecise. Although people are labelled at school so they can get support, once they leave school, there isn't a clear mechanism for labelling them unless they are for any reason referred to a psychologist or psychiatrist.

### Why label?

Like many issues in learning disability, the question of labels is a fraught one.

Many people with learning disabilities question the value of the label and some go as far as to blame the label for some of the difficulties they experience. Remember Charlene in Video 1 saying the label makes her feel ten times worse?

'Label jars, not people' has long been a popular slogan of the civil rights movement of people with learning disabilities.



**Figure 5** People with learning disabilities have criticised the use of labels for many years

On the other hand, there are arguments in favour of labelling. Academic statisticians argue that it is vital to count how many people there are who are likely to need support, who will need housing when parents become too frail to care for them, and who should be flagged as needing special provision when they visit the GP or other health services.

Clare, the mother of Elinor, has strong views on this:

If I am asked about Elinor I don't say 'she is labelled learning disabled', or 'she has a cognitive impairment', I say she is learning disabled or has a learning

disability. I need a way to describe her such that I don't have to go into complicated explanations as to why she hasn't gone to university, got a job, got a relationship, etc., and why my life turned out the way it has. Also it is the name, the description, the 'label' that unlocked the support she, and I, needed for her to have a good life.

### Activity 6 Pros and cons of labelling

Allow about 10 minutes

1. Click the link below to answer the poll on whether you think people should be labelled as having a learning disability.  
[Link: Labelling](#)  
Once you have submitted your choice you can then see how others have voted.
2. Now watch this video of Charlene and Terry discussing labelling. As you watch, note down up to three positives and three negatives of having a label given by Charlene and Terry in the video.

Video content is not available in this format.

#### Video 6



*Provide your answer...*

#### Answer

Positives:

- Learning disabilities need to be talked about more and labels are a way of opening up the conversation.
- You need categories if you are on benefits.
- People with learning disabilities need help and the label can point out who needs that help.

Negatives:

- It makes you feel bad - 'You feel ten times worse'
- It sets you apart from others - 'We are just humans trying to get on with our lives'
- It is misleading and can affect other people's views about what a person can and can't do - 'We're just slow, screw it up and throw it away'.

Charlene and Terry have strong views on labels and at times have different opinions to one another, which highlights how tricky the subject is.

3. Click the link below to answer the poll which again asks your position on labelling. You should tick the three statements you most agree with.

[Link: Labelling \(II\)](#)

Once you have submitted your choice you can then see how others have voted.

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#### Answer

1 to 4 are arguments against labelling, 5 to 9 are arguments in favour. Were you conflicted?

One of the difficulties is that you don't know whether the label unlocks any support. Only 11% of the adults who have been counted as having a learning disability in England get long-term support from Councils. Others manage without such support.

---

In this section you've discussed whether labels are a good thing. This is a debate that you will return to throughout this course.

The next section is about human rights. The labelling discussion has a bearing on this, and you will return briefly to this discussion in the final section of Session 1.

## 8 Human rights

If people with learning disabilities are labelled as such, does this mean their rights as humans are undermined? In this final part of the session, you will consider this question.

### Activity 7 What are people's rights?

Allow about 5 minutes

Choose the option from the list below which you think is correct.

- ☐ People with learning disabilities are entitled to the same rights as any citizen of the UK.
- ☐ People with learning disabilities are entitled to most of the rights others enjoy.
- ☐ People with learning disabilities are entitled to a few of the rights that others enjoy.

#### Discussion

Did you get this answer right? People with learning disabilities are entitled to exactly the same rights as everyone else. How did people obtain these rights? Watch the animation below to find out.

Video content is not available in this format.

#### Video 7 A timeline of rights



This animation shows that people are entitled to the same rights as other people. However, lots of things can stand in the way of people exercising their rights. You will look at these next.



## 8.1 Challenges to upholding rights

While in law people with learning disabilities have the same rights as other citizens, this is not always the case in day to day life.

### Activity 8 The battle for equal rights

Allow about 5 minutes

Watch this video of Dr Lee Humber and Dr Simon Duffy talking about the challenges of ensuring people with learning disabilities have equal rights.

Video content is not available in this format.

#### Video 8



Lee and Simon drew attention to a number of things that can prevent people having equal rights. Write down at least three of them.

*Provide your answer...*

#### Answer

The barriers Lee and Simon identify include:

- lack of education
- poor housing
- lack of employment opportunities
- poverty
- low expectations
- people not knowing they have rights

- government money being spent on the wrong things.

People with learning disabilities definitely have equal rights in law, but may find it difficult to realise their rights. Later in this course, you will explore why this is so.

If you want to know more about the Human Rights Act, click [here](#) for a poster produced by the British Institute of Human Rights.

## 9 This session's quiz

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Well done – you have reached the end of Session 1. You can now check what you've learned this session by taking the end-of-session quiz.

[Session 1 quiz](#)

Open the quiz in a new tab or window by holding down Ctrl (or Cmd on a Mac) when you click on the link. Return here when you have finished.

## 10 Summary of Session 1

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In Session 1 you have heard about the experience of having a learning disability from people who can speak about it for themselves.

You have also considered how it is possible to find out what life is like for people who literally do not have a voice, who cannot communicate in words, but who can communicate through their behaviour, facial expressions and other means. People who know them well, often their families, become skilled at interpreting these types of communication.

You have also learned about the definition of a learning disability, considered some of the challenges of knowing who has a learning disability, and thought about the pros and cons of labelling.

Finally, you have begun to consider the question of rights, and some of the barriers to realising these rights for people with learning disabilities.

In this session you explored:

- what a learning disability is
- the different labels that have been used to describe people with learning disabilities and how people feel about those labels
- what life is like for people with more severe or profound learning disabilities
- some basic facts about the lives of people with learning disabilities
- people's rights.

In the next session you will discover more about the changing views of learning disability over time, which explains in part why rights and labels are such important topics.

You can now go to [Session 2](#).

## Want to know more?

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- Balance of Rights video: <https://vimeo.com/262190581>
- QCF Introduction to Learning Disabilities 'Understanding the Nature and Characteristics of Learning Disabilities':  
<https://nadp-uk.org/wp-content/uploads/2015/02/QCF-intro-to-LD-sample.pdf>
- Social History of Learning Disability Research Group Education Resources Activities 1 and 8:  
<http://www.open.ac.uk/health-and-social-care/research/shld/education-resources>
- EasyRead version of the UN Convention on the rights of disabled persons:  
[https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment\\_data/file/345108/easy-read-un-convention.pdf](https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment_data/file/345108/easy-read-un-convention.pdf)
- Chris Hatton's blog provides up to date analysis of learning disability statistics – including where people live:  
<https://chrishatton.blogspot.com/2019/01/where-are-we-at-with-social-care-for.html>
- If you want to know more about the Human Rights Act, click [here](#) for a poster produced by the British Institute of Human Rights.



# Session 2: History: different approaches to learning disability over time

## Introduction

In this second session, you will learn how ideas about learning disabilities have changed over time. It's a little known history, but an important one if you are to understand the lives of people with learning disabilities today.

You will learn about the recent past through watching an animated timeline, *Present in My Past*, made by Purple Patch Arts, and through studying the lives of two women – Mabel and Bernie. Both Mabel and Bernie were born in the mid-twentieth century and lived through momentous changes in the way learning disabilities are thought about.

To start this session watch this video which introduces Mabel Cooper.

Video content is not available in this format.

[Video 1](#)



Looking at this recent history, you will begin to understand why human rights have been problematic for people with learning disabilities, and why there was a need for a special UN Declaration for Disabled People.

In this session you will explore:

- the different ways learning disabilities have been viewed since the 18th century
- life for people with learning disabilities who lived in institutions in the 20th century
- life for people with learning disabilities who lived in the community in the 20th century
- how learning disability policy has changed over time.

The history you will cover in this session is a western one, applying to the UK, and to some extent other English-speaking countries like the USA, Canada, Australia and New Zealand. It would be a different story if other parts of the world were considered; regrettably there is not time in the course to cover this. If you wish to find out more, you will find ideas in the 'Want to know more?' section at the end of the session.

## 1 From the 1700s to the mid-twentieth century

The Industrial Revolution, which started in the UK in the late 1700s, is the name given to the process in which society changed from being primarily agricultural to one where people migrated to live in towns and worked in factories.



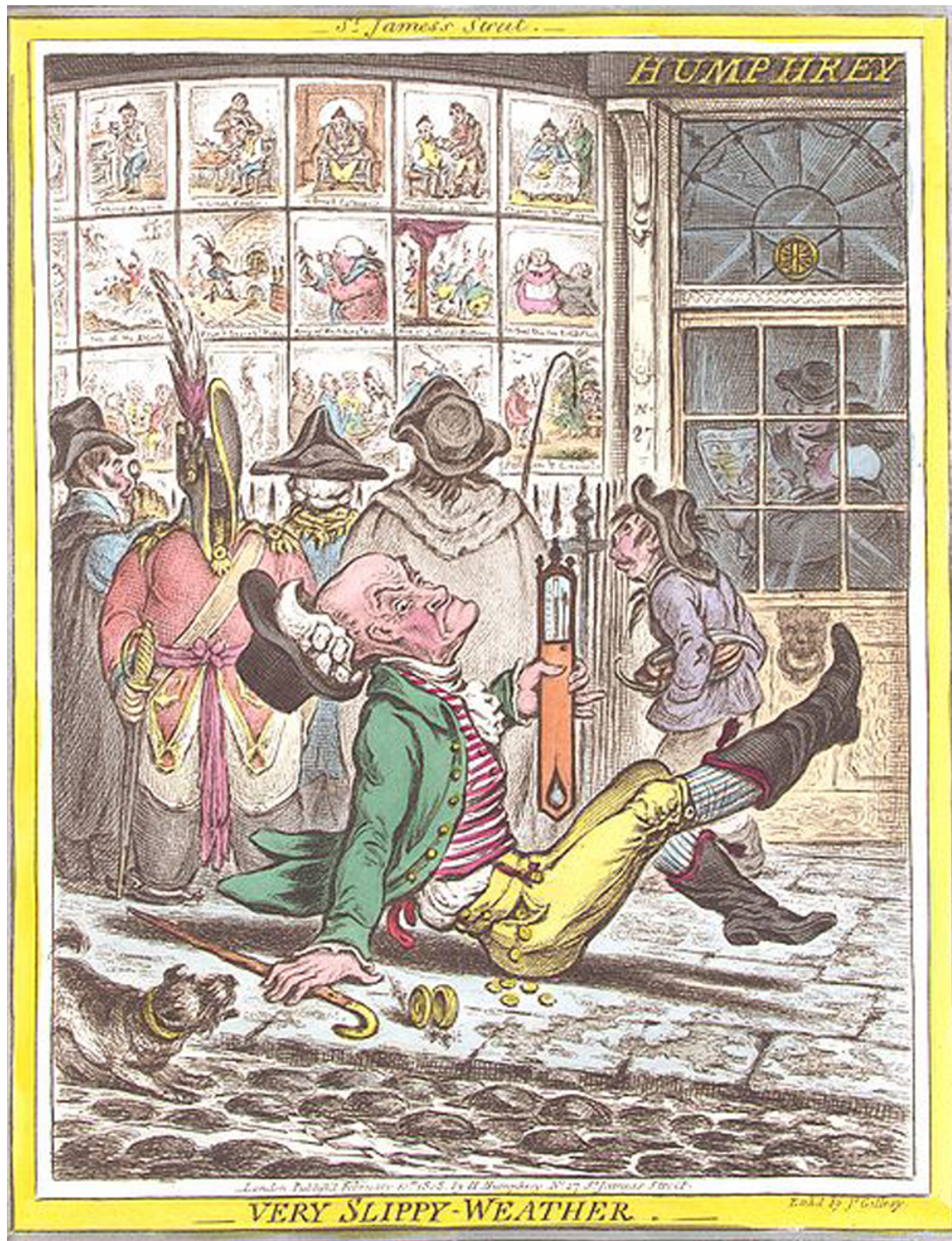
Before the Industrial Revolution there were many jobs that could be done by people with learning disabilities, such as scaring crows, caring for animals and running errands. First, listen to historian Simon Jarrett in Video 2 who argues that society was far more inclusive of people with learning disabilities in that period.

Video content is not available in this format.

#### Video 2



According to Simon, people in the 18th century had different ideas about intelligence. They believed that there were different types of intelligence, all of which were equally valuable. They believed that they could identify a person they called an 'idiot' by what he or she looked like, but that didn't mean s/he was shunned or shut away. For example, they were less a figure of fun than the clever wealthy man who slipped on the ice while reading his thermometer because he lacked common sense, in Gillray's cartoon (Figure 1).



**Figure 1** Gillray's cartoon 'Very Slippery Weather' shows a man with learning disabilities in the background but the figure of fun is the clever man who slipped on the ice

However, as the Industrial Revolution made paid work more mechanised, so people with learning disabilities found it increasingly difficult to fit into the workforce. It was this that made them into a 'problem'.

### Activity 1 Learning disabilities timeline – 1700s to 1950

Allow about 10 minutes

Watch Video 3, which shows an animated timeline of the main events in learning disability history, then answer the questions below.

Video content is not available in this format.

**Video 3**



1. The Mental Deficiency Act brought in provisions for the institutional treatment of people with learning disabilities in the UK. In what year was it introduced?
  - ☐ 1813
  - ☐ 1883
  - ☐ 1913
2. In some countries, people with learning disabilities in the 20th century were not permitted to marry, or have children, true or false?
  - ☐ True
  - ☐ False
3. How many people with learning disabilities were estimated to be living in institutions in England and Wales in the early 1950s?
  - ☐ 15,000
  - ☐ 25,000
  - ☐ 55,000

You have just covered two centuries in a very short time! To find out what some of these changes meant for people, you will be following the stories of two women, Mabel and Bernie, both born in the mid-twentieth century. In the next section you will learn more about the history of learning disability institutions.



## 2 The institutions

The institutions set up after the 1913 Mental Deficiency Act dominated the lives of many people with learning disabilities and their families for much of the 20th century. As the narrator in Video 3 says, about 55,000 people were housed in them in the 1950s.

We know a lot about life in these institutions because of people like Mabel Cooper, once a patient in St Lawrence's, Croydon. Mabel became a campaigner against institutions after she left and helped to spread the word of what it was like to live in an institution. She was awarded an Open University Honorary Degree for her work in 2010.



**Figure 2** Mabel Cooper, pictured on the right, receiving her honorary degree

In them days if you had learning difficulties or anything that's where they used to put you. They didn't say, 'Oh, you could go into a house and somebody would look after you.' They would just say, 'You, you've gotta go into a big hospital' and that's it. Years ago, if you wasn't married and you had a baby, that was a

disgrace and they would say, 'Oh the mother goes to a workhouse or a loony bin' as they had in them days, or the mother went into a workhouse or a loony bin and the child was put in care. I think that's why there was more women.

Mabel Cooper.

Mabel explains that it was all about keeping men and women apart so they could not have children. This was because it was believed that learning disability was inherited, passed down the generations. Therefore it was deemed necessary to stop learning-disabled people having children.

This is known as the science of eugenics, as mentioned in Video 3, which you watched in Activity 1.

## 2.1 The geography of institutions

Between the end of the nineteenth century and 1970, numerous institutions were created to house thousands of people with learning disabilities. Institutions and hospitals (or 'long-stay' hospitals) refer to the same thing. They were places where lots of people with learning disabilities were forced to live together. Most have now been demolished or converted, often to luxury private accommodation.

### Activity 2 Find your local institution for people with learning disabilities

Allow about 10 minutes

Find out where institutions in your area were located by clicking on this interactive map. You should open the link in a new tab by pressing Ctrl (or Cmd on a Mac) when you click on the link.

[Link: Long-stay mental deficiency hospitals in England, Scotland and Wales](#)

Once you find it, you could go and look to see what, if anything, remains of these institutions. Is there anything to tell you that this was a place where several thousand people spent their lives, and died? In many places there are no memorials.



**Figure 3** (a) Cemetery at Leavesden Hospital, Herts; (b) a male villa at Prudhoe Hospital, near Newcastle

Provide your answer...

## 2.2 Life in an institution

To find out about living in institutions, you will now turn again to Mabel Cooper. Mabel was born in 1943 and lived in institutions for much of her early life. In later life Mabel became a campaigner against institutions and joined The Open University's Social History of Learning Disability Group. This gave her the opportunity to tell her story, and to find out more by looking at her care records. In the next video in Activity 3, Mabel talks you through her experiences, starting with how she came to be in the care system in the first place.

### Activity 3 Getting into the care system

Allow about 15 minutes

Watch this video in which Mabel describes how she came to be in the care system and note down the reasons she gives.

Video content is not available in this format.

#### Video 4



*Provide your answer...*

#### Answer

Mabel's mum was begging, so was homeless with Mabel as a baby. When they were separated, Mabel was put into children's homes where she took a test and was told she needed care for the rest of her life.

Mabel remained in an institution until she was in her mid-forties.

Did Mabel's story shock you? Maybe you think that happened a long time ago, and that it's different today. Unfortunately, even today there are people who get caught up in the care system and are housed far from their families. You will learn more about that in Session 8.

## 2.3 Life in St Lawrence's hospital

Mabel spent many years in St Lawrence's hospital. In Video 5 in the next activity you will hear her describe her life there.

### Activity 4 Living in St Lawrences

Allow about 15 minutes

Watch the video below and note down the contrasts Mabel makes between her life at St Lawrence's and her life in her own home.

Video content is not available in this format.

#### Video 5





*Provide your answer...*

#### Answer

Mabel noted that in hospital she had no privacy or even her own clothes. She described it as being like a prison and noted how she was 'pulled about'. The most significant contrast Mabel found between her life at St Lawrence's and her life in her own home was being able to choose what to wear.

Mabel finally left St Lawrence's in the 1970s. She died in 2013. You will return to Mabel's story later in this session, but you will now meet Bernie, born only seven years later than Mabel, but whose life took a different turn.



## 3 Life in the community

Bernadette Lee, or Bernie, was born in 1950, in Watford, Hertfordshire.

Unlike Mabel, Bernie spent only a short time in an institution (Cell Barnes). Instead she spent most of her life living with her family, and then later in a residential home, before finally moving into her own flat when she was 57. This was despite the fact that, when Bernie was born, there was very little support for people with learning disabilities who did not live in institutions.

### Activity 5 Bernie's early life

Allow about 10 minutes

Watch Video 6 in which Phil, Bernie's older brother, talks about his sister's early life, then answer the questions that follow.

Video content is not available in this format.

#### Video 6



1. How did Bernie and Phil's mum learn that her daughter had Downs Syndrome?

*Provide your answer...*

#### Answer

She was told when her daughter had a check-up that she was 'mongoloid'.

2. How did that affect her, according to Phil?

*Provide your answer...*

#### Answer

She appears to have been shocked, so shocked that she almost walked into the road until her sister found her.

3. Why did Bernie end up in Cell Barnes?

*Provide your answer...*

**Answer**

It's not absolutely clear why Bernie went into Cell Barnes, but Phil, only a young child himself at the time, believed it was because another child had been born and his mother was struggling to manage.

4. Why was this a traumatic memory for Phil?

*Provide your answer...*

**Answer**

Phil's memory is of his little sister waving her arms to ask to go home with the family after visits. Even 60 years later, this memory brings tears to his eyes.

Bernie's experiences were not unusual in the 1950s. Many families who had children with learning disabilities at this time were told that the best thing they could do was put the child in a home, forget about them and try for another child. There seemed to be no efforts to offer practical support or advice and families were just left alone to manage if they decided to care for their child in the family home. If they could not manage, then an institutional place was the only option.

Eventually things did get better, but only slowly. You will continue the story by building on the timeline from the late twentieth century to early twenty-first century.

## 4 The late twentieth and early twenty-first century - things getting better

As Bernie's life story shows, things were still very difficult for people with learning disabilities and their families in the 1950s. But thinking and policy were slowly beginning to change. You learned about two things that contributed to this improvement in the previous timeline in [Activity 1](#):

- Judy Fryd started a parents' campaigning group which later became Mencap (1946)
- The NCCL criticised the practice of keeping people locked away (1950).

Other factors also began to make institutions seem like an old fashioned and inhumane form of care:

- New ideas, like 'normalisation', began to circulate. Normalisation is the view that people with learning disabilities are entitled to a normal or 'ordinary' life, just like anyone else.
- It became costly to staff and run hospitals to what the public considered to be an acceptable standard, particularly after the press began to expose the appalling conditions in some hospitals, like Ely, South Wales, in 1969.
- Families working together in organisations like Mencap, Enable, Downs Syndrome Association and National Autistic Society campaigned for community services and for people with learning disabilities not to be discriminated against.
- Research began to show that people with learning disabilities did better and learned more in homely environments than in large, overcrowded hospitals.

Gradually from the 1970s hospitals began to close (that was when Mabel Cooper left St Lawrence's). Governments invested in community services, like day centres, where people could go to spend the day, and residential homes, where they could live as alternatives to hospitals or the family home.

In the next activity, you will continue this story and review the timeline from the mid-twentieth century to the present.

### Activity 6 Learning disability through time

Allow about 15 minutes

Watch Video 7 and then answer the questions below.

Video content is not available in this format.

[Video 7](#)



1. In which year was the Ely Report, which exposed the poor conditions of people with learning disabilities living in long-stay hospitals, published?
  - ☐ 1959
  - ☐ 1969
  - ☐ 1979
2. The Jay Report, published in 1979, said people with learning disabilities should be able to enjoy 'normal' lives, true or false?
  - ☐ True
  - ☐ False
3. Which soap opera introduced a character with learning disabilities in 2006?
  - ☐ Coronation Street
  - ☐ EastEnders
  - ☐ Hollyoaks
4. The Panorama programme in 2011 revealed details of the abuse people had experienced in a private hospital, true or false?
  - ☐ True
  - ☐ False

Bernie's experiences mirror these social shifts. After leaving Cell Barnes in the 1950s, she initially moved back in with her family and then progressed to living in her own flat, which, at the time of writing (2019), is with support from staff who have known her for 15 years.

## 4.1 A changing policy landscape

Until 1971, people like Bernie were labelled 'ineducable'. There was no school place for her.

Watch this video in which Bernie's brother, Phil, explains.

Video content is not available in this format.

### Video 8



Bernie's life began to change in response to the 1971 White Paper, which said more community services were needed for those with learning disabilities. She first of all got a place at a training centre, which provided day time activities and non-paid work, and then moved into a residential home when her parents reached their seventies and decided they needed to find Bernie a home of her own. Both were set up in response to the Government's paper.

However, it was after the Government's White Paper, *Valuing People*, in 2001 that Bernie's life really changed for the better.

### Activity 7 Bernie's story

Allow about 10 minutes

Watch Phil talking about how Bernie's life changed after Tony Blair's Labour Government introduced 'supported living' following the 2001 *Valuing People* White Paper. As you watch, note down what it is about supported living that has made such an improvement to Bernie's life.

Video content is not available in this format.

### Video 9



Provide your answer...

**Answer**

The main improvements Bernie has noticed in her life since the *Valuing People* White Paper include:

- She has her own self-contained flat.
- She has 26 hours of support per week from staff who have known her a long time.
- She has a full programme of activities.

Things have certainly come a long way since the only resource available to Bernie was Cell Barnes hospital.

## 5 The present

There have undoubtedly been significant changes for the better in the lives of people with learning disabilities since the large institutions closed. Bernie is not alone in enjoying a far better quality of life. However, the fight to secure the gains made since 1950 is not over. One of the big debates is around inclusion versus specialist provision.

*Valuing People* made 'inclusion' one of its four principles. This has subsequently been interpreted by governments as meaning that specialist provision, such as the day centre Bernie attended for so long, might be closed in favour of encouraging learning-disabled people to join in the leisure activities other people enjoy. This can be all well and good in theory, but sometimes this can raise practical problems, like affordability, discrimination, access and transport.

Clare, Elinor's mother, discusses the problems that are still faced in the present day:

One of the problems, despite the substantial and welcome changes in attitude that *Valuing People* helped happen, has been a tendency to throw the baby out with the bathwater, so to speak. And for me it speaks to the near impossible task of speaking about different levels of learning disability at the same time. There are day centres that offer opportunities for friendship and meaningful lives – my daughter goes to one 2 days a week – particularly for people with more severe learning disabilities.

The closure of many day centres did not lead to better quality of life for many people rather the reverse, as actually it has been difficult to find ways of providing 'community activities'. In fact it can increase social isolation.

Employment is not an option for people like Elinor. Family carers have relied on the regular hours of day centres to enable them to go out to work. If people are living with their families, the needs of everyone should be taken into account [Care Act 2014] and it's asking a lot of families to manage all their relative's support from home. As family carers say sometimes (though I didn't feel this) they don't want their home to become a work place, or manage staff.

The key issue here is choice: not getting rid of day centres or village communities but offering many alternatives so people can choose. These alternatives should offer something to the immense range of different and diverse people that make up 'people with learning disabilities'.

You will encounter similar debates throughout the course, particularly in Session 8.



## 6 This session's quiz

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Well done – you have reached the end of Session 2. You can now check what you've learned this session by taking the end-of-session quiz.

[Session 2 quiz](#)

Open the quiz in a new tab or window by holding down Ctrl (or Cmd on a Mac) when you click on the link. Return here when you have finished.

## 7 Summary of Session 2

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In this session you have been considering how ideas about learning disabilities have changed over time: from the 18th century, when people who would now be considered hard to employ could perform useful jobs, to the dark era when people with learning disabilities were regarded as a danger to the health of the nation, and the extremes of Nazism.

Changes made since the Second World War have meant that it is possible for many people with learning disabilities to live longer and have enjoyable lives. However, the past casts a long shadow, and is one of the reasons that the question of equal rights is a sensitive one. Not so long ago, many people with learning disabilities were deprived of the right to freedom, and for some it is still under threat.

In this session you explored:

- the different ways learning disabilities have been viewed since the 18th century
- life for people with learning disabilities who lived in institutions in the 20th century
- life for people with learning disabilities who lived in the community in the 20th century
- how learning disability policy has changed over time.

You can now go to [Session 3](#), which focuses on the experiences of families, and what it's like to support someone with a learning disability from the point of view of being a parent or a sibling.

## Want to know more?

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- On the history of the last 50 years, see Jan Walmsley's *The Road to Citizenship* in the Inclusive Archive. There is also an easy read version:  
<https://inclusivearchive.org/story/6/the-road-to-citizenship-by-jan-walmsley/>
- The Open University History of Learning Disability Education Resources, particularly *No Longer Shut Up* (full version), Activities 3, 4 and 12, and Jan Walmsley's *Institutionalisation: An Historical Perspective*:  
<http://www.open.ac.uk/health-and-social-care/research/shld/education-resources>
- For differences across 12 countries:  
Walmsley, J. and Jarrett, S. (eds) (2019) *Transnational Perspectives on intellectual Disabilities in the twentieth century: People, Policy, Practice* Bristol: Policy Press.
- For family stories:  
Rolph S et al (eds) (2005) *Witnesses to Change: Families, Learning Difficulties and History* Kidderminster: BILD.
- For patients' memories of institutions:  
Keilty T and Woodley K (2013) *No Going Back*  
<https://www.centreforwelfarereform.org/library/by-date/no-going-back.html>
- For staff reminiscences of working in institutions:  
Jan Walmsley and The Finding Out Group *A Modern Hospital*  
<https://www.centreforwelfarereform.org/library/by-az/a-modern-hospital.html>
- More detailed timeline:  
<http://www.open.ac.uk/health-and-social-care/research/shld/timeline>



# Session 3: Families

## Introduction

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This week you will be thinking about the families of people with learning disabilities.

Video content is not available in this format.

### Video 1



Families have always been the mainstay of care for people with learning disabilities. In 2015, over 44,000 of the people identified as having a learning disability in England were living with families – 36% of the total. In Wales, the figure was 53% (2018), in Scotland somewhat lower, at 30%.

Whether people stay in the family home, leave it to live independently, or are supported by paid staff, families play an exceptionally important role in the lives of many people with learning disabilities.

In this session you will explore:

- how family carers and paid support workers can work together
- why people with learning disabilities and their families may feel excluded from mainstream society
- the family dynamics when an adult with a learning disability continues to live with parents well into adulthood.

## 1 Family experiences

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In Session 1 you heard from people with learning disabilities. You will now hear from some people whose close relatives have a learning disability.

## Activity 1 Hearing from families

Allow about 15 minutes

For this activity you will be watching two family members talking about their relatives with a learning disability. They share their hopes and fears. As you watch, note down the main issues they mention. You might like to highlight certain words or phrases that recur and any underlying ideas that you notice.

Video content is not available in this format.

### Video 2



Provide your answer...

### Answer

Here are some of things that the family members mentioned:

- What will happen when I'm gone?
- Fear/ anxiety
- Love and devotion
- Grief
- Desire to protect
- Worry
- Isolation
- A lovely person to be with
- Intense emotion.

The emotions for those who have a relative with a learning disability are mixed. Phil, whose sister Bernie you met in Session 2, has spent his life looking out for Bernie but has loved having her as his sister: as it has had a positive impact on his life and given him a greater understanding of others. While many relatives would agree with this, they would at the same time worry about what the future holds, particularly when they are no longer there to care for them. You will look at this in more detail next.

### Box 1 What will happen when I'm gone?

Looking ahead to a time when parents or relatives are not there to keep that watchful eye has always been stressful for families. In Video 2, both Jo and Owen talked about their fears for a time when they are not there to protect their relative. The title of a book published in 1981, *After I'm Gone what will happen to my handicapped child?* (Sanctuary, 1981) sums up one of the major fears of families to this day.

In Video 2, you heard Jo talking in her poem about the 'fiercest watchdog/who would not sleep for a hundred years', and Owen saying that many families wish their son or daughter would die first. This reflects some of the struggles families have in trusting other people to take care of their daughter or son, brother or sister.

Next you will consider the sense of exclusion family members feel in society.

## 2 Disabled by association

In Session 1, Cian, Charlene and Terry talked about a sense of exclusion they felt from society.

Do families share this sense of not really belonging that people with learning disabilities talked about?

### Activity 2 Disabled by association

Allow about 10 minutes

Watch the video below. You may remember some of this content from Session 1. What do you understand the term 'disabled by association' to mean?

Video content is not available in this format.

#### Video 3



*Provide your answer...*

#### Answer

The reason parents and siblings can feel excluded is because of a fear about what other people think about their disabled relative, and also how others will react.

According to Bhavin's mum, Niroo, they are 'disabled by association because wherever you go they look at you, you know'.

According to Jignesh, Bhavin's brother: 'There were many things I would see a lot of my friends and their families doing which actually we as a family could never do. Very rarely could we go away as a family together.'



## 2.1 Living different lives

The Equality Act 2010 made it unlawful to discriminate against disabled people and their carers. However, the law alone cannot solve the problem of stigma and discrimination.



**Figure 1** People with more severe learning disabilities are often very reliant upon their families

The reality for many parents and other family carers where people have severe learning disabilities is that, as the child grows up, the distance between them and their peers grows. Their children often do not:

- leave home to get a job, go to University or travel
- set up their own household
- set up home with a partner.

If their son or daughter continues to live at home, carers, usually mothers, may give up work due to the difficulties of finding reliable respite care, or the need to meet their medical needs. This can lead to financial difficulty, poverty and isolation.

Some family carers report health problems due to stress and, in some cases, the sheer hard physical work of moving and providing personal care for their relative.

Parents and sometimes siblings can also find that their main social role is as a carer, which then sets them apart from their peers and contemporaries too.

## 3 Change and no change for families

In practice, families, mothers in particular, have always been the main providers of care for people with learning disabilities. In the late 1960s, roughly half of adults with learning disabilities lived with their families (Walmsley, 2006). Recent estimates suggest the current figure is 36% in England (Public Health England, 2016), but in Wales approximately half of people with learning disabilities continue to live in the family home. It is not a surprise that this is the case. Very often people with learning disabilities do not get enough support through social services, and families frequently step in to fill the gap. But how does this feel?

### Activity 3 Change and no change

Allow about 10 minutes

Read Sue Wilson's account of her life with her children, James and Jennie.

Note down what Sue says about the help received from social services.

#### Family life

After he [James] was born, I knew that my marriage was very unhappy, but I knew that I could not face life as a single parent with one disabled child, so I made a conscious decision to have another child. I felt it was important for James to have at least one brother or sister, to have some sort of normal life. When I was a single parent with them, I think it was easier having two children than one.

When James and Jennie were small, it was very difficult to cope. I had a twin buggy that I used to have given to me regularly by social services. It would only last a few months and James would break it and they'd send me another one. He must have been in a pushchair until he was well over five or six. So Jennie was walking and running long before he was, and she's two years younger. She was out of nappies before him and talking. But she still had to get strapped in the twin buggy next to James because I couldn't cope with them.

I think it's been quite hard for Jennie. I think she's suffered quite a bit of neglect: her needs have had to come second to James's a lot of the time. It's been hard for my younger son [Joel] as well, particularly when Joel has had to look after James, helping me to bring him up. He has been able to do that for him for a long time. I think James finds that hard.

We had no help from social services. I tried to get help but he was so violent, he really used to punch Jennie hard for no reason, his aggression was directed at Jennie. He grew from five foot two to six foot two in twelve months, so he had all that testosterone flowing round his bloodstream, he didn't know what to do with his anger. At that point, that was when I felt I couldn't cope any longer. Jennie was subjected to tremendous amounts of violence, and I tried to get respite care. We tried to get some sort of placement for him; we tried everything, and we got nothing.

(Rolph et al., 2005)

*Provide your answer...*

**Answer**

Sue got some practical support when James was young (in the form of a twin buggy provided by Social Services). But at the point when the family really needed help – when James became quite violent during adolescence – they received no support at all.

Sue is not alone in feeling abandoned by social services. Jan Walmsley, one of the course authors, quotes many similar instances in a chapter on families' experience of social work (2019).

It is understandable that social workers prioritise people in immediate need, not those who appear to be happily managing in the family home. However, the results can be traumatic, particularly when parents die after a lifetime of caring.

I met Sam (not his real name) in the course of research into supported living in a London borough. He was in his early 60s. He seemed sad. He tore at his shirt when with me. Staff explained that he had come into the house after his mum had been taken ill two years earlier. While she was still alive his sister would come to take him to visit his mum at weekends. He still packed his case on a Friday, and waited at the door. But his sister never came. The staff did not know whether he understood that mum was dead. They did not know where mum was buried. He had not been to the funeral because his sister thought it would upset him. His sister had not been in contact since their mother had died. They did not know how to contact her.

(Walmsley, 2019)

This story is not unique. It is hard for most people when parents die. How much more so, if you have spent your whole life with them until late middle age. This is compounded by a reluctance to talk about death in case it is upsetting for the person.

## 4 Family advocacy and family carers

Families have not taken neglect lying down. Banding together in organisations like Mencap and Enable (Scotland), families have fought hard to get their roles and needs recognised. Play the slideshow below to see some of the actions families in the 1950s and 1960s took.

Video content is not available in this format.

**Slideshow 1** Activities undertaken by parents to create change

### Families fought to change things in the 1950s and 1960s

- They organised seaside holidays
- They set up services like residential homes and nurseries
- They raised money through organising events like pram races
- They offered one another mutual support
- They provided a social life for their sons and daughters
- Gradually from the late 1960s local authorities took over running their local services
- By the 1990s all local authorities provided some residential places for adults



The achievements of families fighting for a better life have been enormous. As a result of their efforts, improvements in community services gradually built up in the late 20th century. For example, day centres have offered somewhere to go in the daytime, giving families time free of caring responsibilities, and providing an alternative to employment. Alternatives to living at home or in a hospital, such as hostels, group homes, supported living, and even home ownership or tenancies have also increased.

Meanwhile, financial benefits including Disability Living Allowance and, later, Personal Independence Payment were introduced, while income support had additional disability premiums.

The role of families was slowly recognised by policy makers, particularly as hospitals began to close and 'care in the community' became the policy from the 1980s. Governments belatedly recognised family carers as an important resource who saved them money. The word 'carer' came into use to mean someone, usually a family member, who supported someone without pay.

The National Strategy for Carers, England (1999), the Strategy for Carers in Scotland (1999) and the National Carers Strategy, Wales (2000) paved the way for:

- carers to have their own needs assessed
- support and involvement in decisions
- respite services to let carers take a break
- payment if caring for at least 35 hours a week.

## Box 2 What is a carer?

A carer is defined by NHS England as:

anyone, including children and adults, who looks after a family member, partner or friend who needs help because of their illness, frailty, disability, a mental health problem or an addiction and cannot cope without their support. The care they give is unpaid.

(NHS England, no date)

Under the Care Act 2014 (England), carers are entitled to an assessment where they appear to have needs. This matches the rights to an assessment of the person being cared for. Similar provisions apply across the UK, under the Carers Scotland Act 2016, the Social Services and Well-being Act (Wales) 2014, and the Carers and Direct Payments Act (Northern Ireland) 2002. Carers will be entitled to support if they meet these criteria:

- the carer's need for support arises because they are providing necessary care to an adult
- as a result of their caring responsibilities, the carer's physical or mental health is either deteriorating or is at risk of doing so, or the carer is unable to achieve any of the outcomes as specified in the regulations and as summarised in the section
- as a consequence of being unable to achieve these outcomes, there is, or there is likely to be, a significant impact on the carer's wellbeing.

(Social care institute for excellence, 2014)

Carers can claim money, if caring for more than 35 hours a week. In 2019, this was £64.60 per week in England, more in Scotland. However, receiving this less than generous benefit can affect other benefits – for example, severe disability premium can be stopped.

## 4.1 An ongoing responsibility

So far the discussion in this session has largely been about people who continue to live with their family, usually parents, well into adulthood. However, this is not everyone. Some young people with learning disabilities do leave home, some to live semi-independently, perhaps with support from paid staff. Despite this, families report that they continue to feel a sense of responsibility.



**Figure 2** Care staff may find themselves supporting people to make decisions about what to eat

For example, Leah is 30 years old. She has a moderate learning disability. She lives in her own flat with paid support workers visiting and her parents also live nearby. She receives Direct Payments, meaning she is in charge of her own budget, and employs her own support. Despite this sense of independence, Sheila, Leah's mum, explains that she is still responsible for making sure everything runs smoothly – and fighting for Leah's rights:

My daughter's support has been in the process of being reviewed for a year now. This involves a stop/start series of meetings with care managers and seniors. The bottom line is a cut in her hours but with no clear justification or assessment. An assessment was undertaken in the spring and it was called an 'outcomes focussed assessment'. The only outcome, however, was a reduction in support they will pay for from 35 hours per week (too much as everyone agrees) to 7 hours per week. The only reason given was that she is 'independent'.

We robustly challenged this 'assessment' and it ended up (eventually) with a senior council officer declaring it inadequate and the whole sorry process started again. Only yesterday we had an email from yet another care manager saying that Leah's support would be reduced to 'take account of her outcomes' (as yet not known or documented).

(Walmsley et al., 2017)

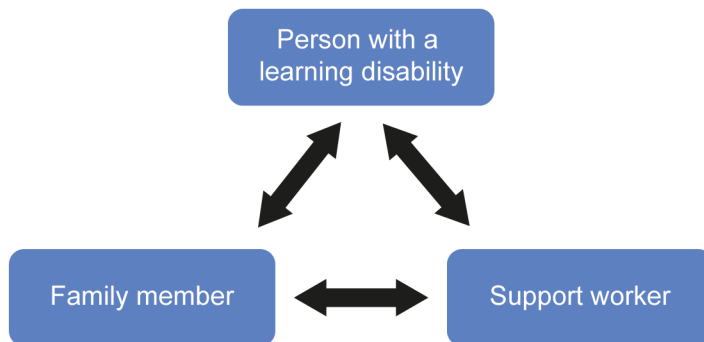
Sheila's experiences are a reminder that parents sometimes feel that the battle to get the best for their sons and daughters is never ending, despite the aspiration that they can live independently.

For many people with learning disabilities, their families are their best advocates. However, some might argue that parents need to learn to 'let go', and accept that theirs is not the only way to offer support. It is this dilemma that you will explore next.



## 5 Choice and conflict

So far in this course, you have seen some of the strains that families experience when relatives have a learning disability. Here you will explore what happens when you bring paid supporters into the picture.



**Figure 3** People with learning disabilities are often supported by both family members and paid care staff

Figure 3 places the person with a learning disability at the top. His or her well-being relies on the family and support worker working in harmony.

This can be quite a difficult set of relationships. The mothers, fathers, sisters and brothers of people with learning disabilities (family carers) bring with them their own history of experiences, some good, some difficult and painful. When relatives reach adulthood, they have to deal with a whole new set of services, social workers and support staff. When these go well, they can be greatly valued by the family and help to improve the lives of the service user. When they go badly, and tensions and conflicts develop, everyone suffers. Difficulties can arise when families see their disabled relative as having a younger developmental age, whereas staff wish to acknowledge them as autonomous adults. Owen, who you met in Section 1, acknowledged that his views changed when he became responsible for his sister Dora.

I recall all the comments that my parents used to say: Make sure Dora is okay; Dora must be looked after. All these thoughts come back to me and it does get a bit scary when you've eventually got to take the leap. The carer doesn't believe that anybody else can care for that person as well as they can. That was certainly the view of my parents and when I was younger I used to think how silly they were. But now that I'm in exactly the same position as my parents were in, I can see exactly what they meant.

(extract from Learn with Us)

A good three-way relationship between the person with a learning disability, their family and the support staff who look after them is important, but not always easy to achieve. The next activity illustrates some of the tensions.

### Activity 4 What should Dora wear?

Allow about 10 minutes

Watch Video 4 in which you hear Owen talk about the clothes that Dora wears. Owen thinks that staff should encourage Dora to wear clothes that don't make her look like 'a clown'. As you watch note down the case for and against Owen's view.

Video content is not available in this format.

#### Video 4



*Provide your answer...*

#### Answer

##### For

- People are less likely to notice Dora.
- People are less likely to poke fun at Dora.

##### Against

- Dora is an adult and should be able to make up her own mind about her clothes.
- Who, other than Dora, is to say what is and is not acceptable? Ian, a self-advocate with learning disabilities who reviewed this course, commented: 'No one should tell someone else what to wear. What's wrong with her clothes?'

It is a simple thing to say people have a right to choose what to wear. But the devil is, as so often, in the detail. What does 'choice' mean? Where it is assumed, rightly or wrongly, that a person with a learning disability does not have the ability to make sensible



decisions, then the scene is set for conflict between the people who believe they know what is best for that person.

## 5.1 Families, culture and support

Deciding who knows best is a very tricky area for families, staff and people with learning disabilities. It becomes, if anything, more complicated when you add different cultures into the mix.



**Figure 4** People with learning disabilities may be supported by care staff from different cultures

Remember Bhavin? He appeared in videos in Session 1 and earlier in this session. One concern Bhavin's brother, Jignesh, has is that the young woman working with Bhavin as his key worker wears revealing clothes, which is not commensurate with his cultural values. Bhavin, a young man, is likely to get excited being in close proximity to a young woman, but Jignesh has felt like he can't tell the worker what to wear.

As you can appreciate this is a complicated scenario and, when asked, people had strong and differing views on it. One person commented: 'you should always dress professionally, and that means taking account of what the client and his family think is right'. However, another, equally vehement, said 'Bhavin needs to learn to relate to all kinds of people. It does him no favours to try to manage his environment to that extent.'

Where do you stand? Although getting all parties to agree can be hard, when you get the communication right, the relationship can be really positive for the person with a learning disability.

## 5.2 Getting the communication right

The next activity asks you to consider good communication between families and support workers, when the person has profound and multiple or severe learning disabilities.

### Activity 5 Ask the family

Allow about 15 minutes

Watch this video of people with profound or severe learning disabilities taking part in performing arts.

Video content is not available in this format.

### Video 5



Now imagine you are one of the drama workers.

1. Write down four questions you would ask a family carer about the person you are working with.

*Provide your answer...*

### Answer

Questions you could have asked include:

- What does s/he enjoy doing?
- What does s/he like to eat and drink?
- Does s/he have any particular medical problems?
- Is there anyone in the group s/he particularly likes to be with?
- Does s/he have any special talents to build on?

2. Write down two ways to share with families what their relative has been doing in the drama class.

*Provide your answer...*

### Answer

Methods for sharing their experience with their family might include:

- A written diary, maybe one where the family member can respond.

- Using an iPad or mobile phone to take photos and share them using social media, email or text. This could also invite response from the carer.

Maintaining positive communication between families and support staff can be time consuming for everyone, but getting it right can have huge benefits.

## 5.3 Living with my family

This final section of this session looks at the perspective of young people with learning disabilities living with their families. The statistics quoted in the introduction to this session showed that it is far more common for people with learning disabilities to remain with their families into adulthood than it is for non-disabled people – though this may be changing for millennials.

In the next activity you will hear Charlene, Cian, Terry, Dayo and Shaun, who you first met in Session 1, talking about living with their families.

### Activity 6 Living with my family

Allow about 15 minutes.

First watch and listen to Charlene, Cian, Terry, Shaun and Dayo talk about living with their family. Then, using cut and paste, put the ideas they mention (shown in the box below) into Table 1 using the headings given.

Video content is not available in this format.

#### Video 6



I love my family to bits	My mum was over protective
I spend too much time with my family	I didn't get the chance to go off to university
I'm always very close to my family	Whenever I go out they always call up to make sure I'm OK
My mum needs my help more than I need her help	They don't treat me like an adult
There isn't much option for me to live independently	My mum is pretty chilled out
My mum was trying to hide me from society	My gran taught me about the birds and the bees

My mum and my dad broke up, it completely went in reverse

**Table 1 Views on living with family**

I like living with my family	I don't like living with my family	Things changed when ...
<i>Provide your answer...</i>	<i>Provide your answer...</i>	<i>Provide your answer...</i>

### Answer

**Table 1 Views on living with family (completed)**

I like living with my family	I don't like living with my family	Things changed when ...
I love my family to bits	My mum was over protective	My mum needs my help more than I need her help
I'm always very close to my family	We spend too much time together	Mum and dad broke up, it went completely into reverse
My mum is pretty chilled out	I didn't get the chance to go off to university	
Whenever I go out they call up to make sure I am OK	My mum was trying to hide me from society	
My gran taught me about the birds and the bees	They don't treat me like an adult	
	There isn't much option for me to live independently	

These responses are as mixed as you might expect, and easily as mixed as the family perspective.

Did you notice how family relationships change over time? Terry in particular spoke about this, as now that his mum is getting on she is in need of Terry's help as well. The relationship is becoming more reciprocal, and better as a result.

## 6 This session's quiz

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Well done – you have reached the end of Session 3. You can now check what you've learned this session by taking the end-of-session quiz.

[Session 3 quiz](#)

Open the quiz in a new tab or window by holding down Ctrl (or Cmd on a Mac) when you click on the link. Return here when you have finished.

## 7 Summary of Session 3

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In this session you have been considering learning disability from the perspective of families, who are often the primary carers even when they live elsewhere. You have learned that families experience very mixed emotions. They may feel oppressed and burdened, concerned about their relative, fearful about the future when they may no longer be around to keep a watchful eye, and yet recognise many benefits from living with and caring for a learning disabled relative.

There can easily be differences of opinion on what's best for the relative, particularly when their disability is more severe. Hence conflict and misunderstandings between family and paid carers over who knows best can occur. However, when families and support workers work in harmony things can work well.

Finally, you heard from young adults with learning disabilities about how they feel living with their families, and how things can change over time.

In this session you explored:

- how family carers and paid support workers can work together
- why people with learning disabilities and their families may feel excluded from mainstream society
- the family dynamics when an adult with a learning disability continues to live with parents well into adulthood.

You can now go to [Session 4](#), which explores education for people with learning disabilities and their experiences of school.

## Want to know more?

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- A comprehensive overview of families (including easy read versions by Jan Walmsley) can be found on the Inclusive Archive of Learning Disability History website, Sections 2 and 5: <https://inclusivearchive.org/about-the-history>
- Carers UK website: <https://www.carersuk.org/home>
- Rolph S., *et al.* (eds) *Witnesses to Change: Families, Learning Difficulties and History* Kidderminster: BILD.





# Session 4: Education

## Introduction

Video content is not available in this format.

### Video 1



Education for everyone – including people with learning disabilities – is a fundamental human right. In the UK, like many other countries around the world – the right to an education is enshrined in law. But people with learning disabilities have not always had this right. And many families would argue that they are still fighting for a quality education for their children.

Today, children with learning disabilities are educated either in inclusive schools (sometimes described as ‘mainstream’ schools) or special schools. Inclusive schools provide education to pupils of all needs and abilities. Special schools provide education **only** to pupils with special educational needs and disabilities. As you will learn in this session, some people believe passionately in promoting inclusive education, whereas other people feel strongly that there continues to be a need for special schools.

In this session you will explore:

- the history of education for people with learning disabilities
- the benefits and challenges of delivering inclusive education
- the role of special schools
- the experiences of the education system for people with learning disabilities.

Before you start, first answer the question in the activity below.

### Activity 1 What's fair?

Allow about 5 minutes

Click the link below to answer the poll on how you think the country's education budget should be spent.

[Link: Deciding how to use the country's education budget](#)

Once you have submitted your choice you can then see how others have voted.

You will return to this question at the end of the session to see if your views have changed whilst studying the course.

## 1 From 'ineducable' to 'included'

You have followed the story of Bernadette 'Bernie' Lee in previous sessions. Watch the video below (which you first watched in Session 2), where Phil Lee talks about his sister's education.

Video content is not available in this format.

### Video 2



Phil's highly charged interview reflects the historical injustice that people with learning disabilities have faced in terms of getting an education. In the UK, for much of the 20th century, children assessed as having an IQ under 50 were deemed to be 'ineducable'. Their families received a certificate confirming this, which meant that they could legally be denied an education.

Click through the slides in Slideshow 1 to see how this gradually changed in the UK from 1970 following the passing of the Education (Handicapped Children) Act.

Interactive content is not available in this format.

### Slideshow 1

### Activity 2 Where children are schooled

Allow about 5 minutes

What proportion of children with special educational needs and disabilities (SEND) do you think are educated in state-funded mainstream primary and secondary schools in England?

- ☐ a) 75-100%
- ☐ b) 50-75%
- ☐ c) 25-50%

### Answer

The data for England collected in 2017 showed that 48% of students with SEND were being educated in state-funded mainstream schools. 44% were educated in maintained special schools. The other 8% were being educated in a mix of independent schools, non-maintained special schools or Pupil Referral Units. Interestingly, this is quite a different picture to Scotland, which has a stronger policy commitment to inclusion. In Scotland, over 90% of children with Additional Support Needs (ASN) are educated in mainstream schools (Scottish Government, 2018), although a proportion of these are schooled in special units on the main site. However, due to differences in how 'SEND' and 'ASN' are defined, it can be difficult to compare figures.

(Source: Department for Education, 2017)

You may have been surprised to learn that despite the national and international policy commitments to inclusive education, less than half of children with SEND actually attend a mainstream school.

## 1.1 Separate or together?

Despite the national and international commitment to inclusive education, many parents find it difficult to secure a mainstream place for their child and are encouraged to seek places in special schools.

Since 2005, the number of children in segregated settings in England has actually been rising. Richard Rieser (2017), from World of Inclusion (an organisation that promotes inclusive education), argues that this is becoming more common-place for two main reasons:

- cuts to school budgets which are making it more difficult for mainstream schools to offer the support that children with special education needs require
- the Government's commitment to setting up more special school academies and special free schools to support 'parental choice'.

OU academics John Parry et al. (2013) have suggested that delivering good inclusive education can be difficult in part because of the historical legacy of special education. This is covered in the next section.

## 2 The role of special education

Before the passing of the Education (Handicapped Children) Act 1970, thousands of children with learning disabilities were being educated in special schools. Many of these schools had been set up by parents, desperate to ensure that their children could access education that would not otherwise be provided by the state (Rolph, 2005). As you saw in Activity 2, a high number of children with special educational needs continue to be taught in segregated settings – in fact, the numbers are rising.



**Figure 1** Special schools have a long history and continue to be popular with some parents

### Activity 3 Reasons to choose special education

Allow about 5 minutes

Can you think of a reason why a parent might continue to opt for a special school for their son or daughter?

*Provide your answer...*

### Answer

Clare Palmer, mother of Elinor, who you met in Sessions 1 and 2, said: 'As a parent of a child with profound learning disabilities, without words, needing total personal care, without the motor skills to hold a pen, without the understanding of what a pen is, what I most wanted was a good special school.'

Parents are often persuaded that special schools will provide an education more tailored to their child's needs, in an environment that will be more nurturing. Some parents have concerns that their children may find it more difficult to develop friendships in mainstream school and that they may be subjected to greater levels of bullying. Cuts to school budgets have also created a climate in which fewer mainstream local schools appear to be equipped to effectively support disabled students. For all of these reasons – and others – many parents continue to seek places for their children in special schools.

The movement to inclusive education for children and young people with learning disabilities has been controversial. While most people acknowledge the right to an inclusive education for children with learning disabilities, there is a lot of debate about how well it works in practice. Even Baroness Warnock, whose 1978 report was instrumental in the shift towards inclusive education, later expressed concerns about the isolation, marginalisation, unhappiness, bullying and disaffection experienced by children and young people with learning disabilities in mainstream settings.

## 2.1 Attending a special school

But what is it like to actually attend a special school?

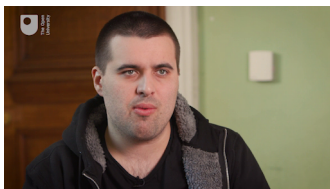
### Activity 4 First hand experiences of going to a special school

Allow about 10 minutes

Watch this video of Dayo, Cian, Shaun and Terry discussing their experiences of special education.

Video content is not available in this format.

#### Video 3



Pick out some of the experiences that people talked about in relation to their experience of special school:

- ☐ Being listened to
- ☐ Being bullied
- ☐ Having opportunities to do extra-curricular activities

- ☐ Not being taken seriously
- ☐ Feeling very supported

While there were some positive experiences recounted by the people on the film, you may have been surprised by how many bad experiences they discussed. This even included a case of abuse not being taken seriously. The film does not convey experiences of school that were highly supportive or nurturing. However, Dayo and Terry did give examples of some of the good things they did while at special school, such as getting involved in sports and drama.

## 2.2 Working in a special school

In Video 3 you listened to people discussing their experience of being a student at a special school. But what is it like to work in a special school? What are the benefits and what are the challenges?

### Activity 5 The benefits of special schools

Allow about 10 minutes

Listen to Clare Savory, Head of Science at Parkside School in Norwich, talking about why she thinks there is still a need for special schools. As you listen, make a note of some of the positive aspects of teaching in a special school that Clare reports.

Audio content is not available in this format.

#### Audio 1

*Provide your answer...*

### Discussion

Some of the positives you might have noted from Clare's account were:

- the children often arrive at Parkside after difficult experiences in a mainstream school. The special school offers opportunities for students to be **less** segregated in Clare's view.
- the school can nurture students' skills and interests.
- the school can also provide support and education that is more tailored to the individual. This can help students' confidence to grow.

Despite calls for a fully inclusive education system, Clare has shown that there can be significant benefits for some students who attend a special school. However, in the next section you will explore some of the benefits and challenges of delivering inclusive education.



## 3 Inclusive education in practice

Advocates of inclusive education argue it shifts thinking away from a '**deficit model**' where the focus is on what a child cannot do, towards a '**social model**', where the focus is on what the school can do to adapt to the child's needs. Proponents of inclusive education also argue that it provides a unique opportunity to model an inclusive world, where non-disabled children can learn to communicate and form friendships with children with learning disabilities through common interests and activities. The argument made is that society can never be truly inclusive if people are separated from one another from school age onwards.

International research (Hehir et al., 2016) has shown that across the world, children with special educational needs benefit academically and socially when schooled in inclusive environments. The evidence also shows that the impact of inclusive education on non-disabled students is neutral or even positive. The argument made is that good inclusive teaching benefits everyone in the classroom.

Despite the research, it can often be difficult for parents and teachers to envisage what a good example of inclusive education looks like. In the next activity you will watch a video about Eastlea School. This will enable you to see a whole-school approach to inclusion.

### Activity 6 Inclusive education in action

Allow about 10 minutes

Watch this video about Eastlea School then answer the question that follows.

Video content is not available in this format.



#### Video 4

Why do you think Eastlea School is able to be so inclusive in its approach?

*Provide your answer...*

#### Answer

There are lots of reasons why Eastlea School is delivering high quality inclusive education. Some things you may have identified are:

- a deep commitment to inclusion through all levels of the school – from the most senior members of staff, to the students
- students are given clear messages about the benefits of inclusion and how they can help themselves, by helping each other
- the school has explored creative approaches to adapting the curriculum, but they talk about these things as very straightforward and simple things to do
- disabled students are very present in the classroom and recreational areas. The school is definitely aspiring to 'inclusion' over 'integration'.

Eastlea School is a model of good practice and shows what can be achieved when the commitment to genuine inclusion is present. But delivering this level of inclusion can also come at a cost, as you will learn in the next section.

## 4 Challenges and benefits of delivering inclusive education

A number of factors can make it difficult to achieve inclusive education in practice, as you will learn in the next activity.

### Activity 7 The difficulties of delivering inclusive education

Allow about 10 minutes

Watch Elaine Cowin, a Special Educational Needs Coordinator (SENCO), at an inner-city primary school, discussing some of the challenges she faces in her day-to-day work. Then complete the table below, reflecting on the challenges and benefits of delivering inclusive education.

Video content is not available in this format.

#### Video 5



**Table 1 Challenges and benefits**

Challenges	Benefits
<i>Provide your answer...</i>	<i>Provide your answer...</i>

#### Answer

**Table 1 Challenges and benefits (completed)**

Challenges	Benefits
There is not enough funding to cover the full costs of educating some children with special educational needs and disabilities in mainstream schools. This means that inclusive schools can find themselves running at a financial loss.	Elaine says that to effectively teach children with special education needs and disabilities, you need to teach well. This means the quality of teaching can be very high in inclusive schools, which benefits all students.

In Elaine Cowin's experience, delivering inclusive education has benefits for the whole school. She argues that it can lead to higher quality teaching which impacts positively on all students. But you may have been surprised to hear about the funding issues which can

mean schools who are inclusive run at a financial loss. Currently, it seems that for some schools, there are simply too many disincentives at play to enable them to deliver what is actually national – and international – education policy.

## 5 This session's quiz

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It's now time to complete the Session 4 badged quiz. It's similar to the previous quizzes but this time instead of there being 5 questions there are 15, covering Sessions 1 to 4.

[Session 4 compulsory badge quiz](#)

Remember, this quiz counts towards your badge. If you're not successful the first time, you can attempt the quiz again 24 hours later.

Open the quiz in a new tab or window by holding down Ctrl (or Cmd on a Mac) when you click on the link. Return here when you have finished.

## 6 Summary of Session 4

It may have come as a surprise to you to learn that children with learning disabilities could legally be denied an education until as recently as 1970. Before this time, parents fought hard to create educational opportunities for their children, and this helped to create the system of special schools that continue to exist today. While national and international policy has emphasised that children with special educational needs and disabilities have a right to an inclusive education, there continue to be many barriers to achieving this.

Have you changed your views of inclusive and special schools now you have completed this session? Below is the same question you were asked at the start of this session – will you give the same answer?

### Activity 8 What's fair?

Allow about 5 minutes

Click the link below to answer the poll on how you think the country's education budget should be spent.

[Link: Deciding how to use the country's education budget](#)

Once you have submitted your choice you can then see how others have voted.

In this session you explored:

- the history of education for people with learning disabilities
- the benefits and challenges of delivering inclusive education
- the role of special schools
- the experiences of the education system for people with learning disabilities

You are now halfway through the course. The Open University would really appreciate your feedback and suggestions for future improvement in our optional [end-of-course survey](#), which you will also have an opportunity to complete at the end of Session 8. Participation will be completely confidential and we will not pass on your details to others.

You can now go to [Session 5](#), which will look at employment and the world of work for people with learning disabilities.

## Want to know more?

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- Go to the World of Inclusion website to learn more about inclusive education:  
<http://worldofinclusion.com>
- The Alliance for Inclusive Education have collected testimonies from people about their experiences of education:  
<https://www.allfie.org.uk/uncategorised/how-was-school/>





# Session 5: Work and employment

## Introduction

Many people with learning disabilities want to work, but in practice very few manage to find and keep jobs. While the employment rate within the general population in England and Scotland hovers around 74-75%, for people with learning disabilities who are known to their local authority, the figure is approximately 6%. The Welsh and Northern Irish governments do not publish data on how many people with learning disabilities are in paid work.

Despite lots of policy focus on getting more disabled people into work, in practice, the numbers of people with learning disabilities in paid work have barely changed at all in recent years. For that reason, it is really important to learn more about what helps people into work, and what the barriers might be.

Video content is not available in this format.

### Video 1



In this session you will explore:

- what helps people with learning disabilities get and keep a job
- what makes it more difficult for people with learning disabilities to get and keep a job
- what is good or bad work for people with learning disabilities.

## 1 The importance of work

While having a job may not be right for all people with learning disabilities, for many, it offers a number of potential benefits. As well as providing an income, work can give people a sense of purpose ('a reason to get up in the morning') and help them to make

social connections. In the video below, listen to Phil Lee talking about a job his sister, Bernie, used to do, and why it was important to her.

Video content is not available in this format.

#### Video 2



Phil argues that the factory job was work that Bernie enjoyed. It also meant that she and Phil shared some 'common ground' and could talk together about their working day. However, when industrial work for people with learning disabilities fell out of favour, this job was taken from Bernie. As you will learn in this session, access to work for people with learning disabilities is often dependent on government policy and funding, and the attitudes of others.

## 2 Finding a job

For many people with learning disabilities, the first hurdle to overcome is getting a job in the first place.



**Figure 1** Job application processes are often not accessible to people with learning disabilities

Often, people with learning disabilities are not encouraged to even apply for work. And if they do, it is not uncommon to hear stories of a person applying for a number of jobs, and never being called for an interview.

### Activity 1 The barriers

Allow about 5 minutes

Why do you think people with learning disabilities are less likely to be put forward for jobs and/or shortlisted for interview?

*Provide your answer...*

#### Answer

Research (Coleman et al., 2013; Roulstone et al., 2014; Mencap, 2018) shows that a number of factors affect people's chances of securing a job. These include:

- discriminatory attitudes towards learning disability
- low expectations about people's capabilities
- a lack of suitable skills or qualifications
- concerns about the level of support a person might need
- lack of personalised and flexible employment programmes.

The Care Act 2014 (England) is clear about the requirement for commissioners to support disabled people to gain and retain work. Despite this, employment levels for disabled people are unacceptably low. It is even harder for people with more complex learning disabilities to find work.

People with learning disabilities and their families also believe that the benefits system can be a barrier to getting a job. This is because if the job doesn't work out it can have an impact on benefits, which leaves people scared to take the job in the first place. It can make people scared to take a paid job in case it doesn't work out, which can have an impact on benefits.

It is also important to acknowledge that for some people with learning disabilities, the ambition of paid work may be unrealistic and not what they or their families want.

## 3 Having a job

Being in work can be a positive experience for people with learning disabilities, but it can also present some challenges.

### Activity 2 Experiences of work

Allow about 10 minutes

Watch this short video of some of the actors from Access all Areas, a theatre company for people with learning disabilities, talking about their experiences of work over the years. Then answer the questions below.

Video content is not available in this format.

#### Video 3



1. Cian's experience at the charity shop was:
  - ☐ fulfilling
  - ☐ boring
  - ☐ met his expectations
2. Dayo describes his acting work with Access all Areas as:
  - ☐ a learning experience
  - ☐ a job that has given him opportunities
  - ☐ a temporary job while he finds something else
3. Terry's job at the college meant he could:
  - ☐ get paid
  - ☐ teach

Video 3 showed that people with learning disabilities have varied experiences of the workplace and finding a job.

4. Unfortunately even if a person with learning disabilities secures paid employment, it is not always easy for them to keep their job. Make a note of the things that might make it difficult for a person with learning disabilities to keep their job.

*Provide your answer...*

#### Answer

Research (Coleman et al., 2013; Roulstone et al., 2014; Mencap 2018) shows that some people with learning disabilities face harassment or bullying when in the workplace. Some people are reluctant to disclose their learning disability to colleagues at work, for fear of being stigmatised. This can result in people not getting the workplace adjustments that they are entitled to under UK Equality legislation which makes it more difficult for them to keep their job.

## 3.1 Included exclusion

Lee Humber, an academic in the social history of learning disability, interviewed people with learning disabilities about their experience of employment over time. His research (2014) showed that people with learning disabilities sometimes experience what he describes as '**included exclusion**' at work. By this he means that even when people hold down their jobs – sometimes for very long periods of time – they don't feel 'part of the team'. For example, here is Margaret, a 51-year old woman with learning disabilities, talking about her employment in a North London biscuit factory:

It was quite a big factory. I never really mixed with the people there. I mostly kept myself to myself. They didn't seem very sociable. They did used to say hello and that but I used to take my sandwiches for lunch. I was mostly on my own there.

(Humber, 2014, p. 283)

Equality legislation (for example the Equality Act 2010) is in place to prevent disabled people from being discriminated in the workplace. But Humber's research shows that in order for people with learning disabilities to have a good experience of work, employers need to do more than merely avoid discrimination. Employers need to take steps to ensure that colleagues with learning disabilities are respected, valued and supported to feel included.

## 3.2 Making reasonable adjustments: making time

A person with learning disabilities who reviewed this session said that in his experience, workplaces aren't always very supportive if you need to work at a slower pace. In the next activity, you will learn how an organisation changed its ways of working to make the workplace more inclusive.

### Activity 3 An inclusive work environment

Allow about 15 minutes

Ajay Choksi has been employed by the Rix Centre at the University of East London as a technical assistant for a number of years. Watch this video of Ajay and his colleagues talking about his work at the University. The first half of the film is focused on what Ajay does at work. The second half of the film focuses on the role of his employer.



This film and its captions were produced by Ajay Choksi. We would like to thank Ajay and the team for making this film for the course.

After you have watched the film, complete the table below. Try to think of at least three points under each column.

Video content is not available in this format.

#### Video 4



**Table 1 Ajay's experience of work**

What is good about Ajay's work?	How have Ajay's colleagues at the Rix Centre supported him at work?
<i>Provide your answer...</i>	<i>Provide your answer...</i>

#### Answer

**Table 1 Ajay's experience of work (completed)**

What is good about Ajay's work?	How have Ajay's colleagues at the Rix Centre supported him at work?
Ajay's job gives him opportunities to socialise with his colleagues	Ajay's colleagues make time to prepare him for certain tasks, like presentations and meetings

Ajay's job is varied and interesting	They make time to reflect on what is working well for Ajay, and what can be improved
Ajay has progressed in the job and is doing new things and taking on more responsibility	They use more visual aids, like diagrams, to enable Ajay to be included
Ajay has become more independent at work	They use simpler language
Ajay has good relationships with his colleagues	They encourage and support Ajay to think about his future plans at work

What may have struck you most about this film is that Ajay appears to be a genuine member of the team. His colleagues adapted their working practices to help achieve this. Taking more time both to prepare and to reflect is not always easy for busy organisations struggling to meet deadlines or with pressures to deliver services or goods. But in this film, Andy Minnion suggests that making the changes needed to create an inclusive workplace can have benefits for everyone.

## 4 Supporting people into work

Although some people with learning disabilities look for work independently, many people are supported through schemes that are publicly funded. These schemes are usually funded by local authorities or the NHS, which view getting people into work as making a positive contribution towards good health and social care.

The National Development Team for Inclusion (NDTi) carried out a research project (Grieg et al., 2014) which looked at what helps people with learning disabilities into employment. They wanted to know if particular approaches were more successful than others, and what the cost of these different approaches might be.

### Activity 4 The cost of supported employment

Allow about 5 minutes

How much do you think it costs on average to help a person with learning disabilities find a new job, or keep a job they already have?

- ☐ £80
- ☐ £800
- ☐ £8000

#### Discussion

In actual fact, NDTi's research showed that on average it costs £8218 to help a person with learning disabilities find or retain work. But this is just an average. The actual spread of the cost was much wider than this. Some services were doing it for as little as £208, and some cost £57,640 per person.

Interestingly, the NDTi's research showed that services that were doing really well at getting people into work, and helping people to keep their jobs, were by no means the most expensive. Further, the research showed that these good employment services also managed to get a whole range of people into work, including people with mild, moderate and severe learning disabilities.

### Activity 5 What works?

Allow about 5 minutes

What things do you think might help improve a scheme's chances of supporting a person with learning disabilities to get and keep work?

*Provide your answer...*

**Answer**

The NDTi's research showed that the most important factors were that the services were highly personalised, with excellent support available both for the individual and the employer.

Their research also showed that the local authority and NHS Trusts who were paying for these support services had a major part to play as well. Employment outcomes are improved when local authorities and the NHS view getting people into work as a real priority.

## 5 Working with other people with learning disabilities

From the turn of the 21st century, opportunities have opened up for people with learning disabilities to undertake paid work where they are seen as 'experts'. Sometimes these opportunities come about through people's involvement in self-advocacy groups. These are organisations run for – and by – people with learning disabilities. You'll read more about them in Session 8.

In the next activity, you will watch Shaun Picken talk about his experience of becoming a consultant through self-advocacy organisation My Life My Choice.

### Activity 6 Self-advocacy as a route to employment

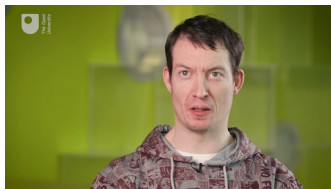
Allow about 10 minutes

Watch this video of Shaun talking about his experience of work at My Life My Choice. As you watch note down:

1. how Shaun's life has changed since he became a consultant with My Life My Choice
2. what type of work Shaun is involved in.

Video content is not available in this format.

#### Video 5



*Provide your answer...*

#### Answer

1.
  - It has given Shaun hope of a working life
  - Shaun has developed more self-esteem
  - Shaun isn't sitting in front of a computer '24/7' anymore.
2.
  - Shaun is a travel buddy for other people with learning disabilities
  - Shaun is a gig buddy, helping other people with learning disabilities to develop a social life
  - Shaun takes part in Care and Treatment Reviews

- Shaun is now a paid consultant for My Life My Choice.

Much of the focus in this session has been on paid work, however Shaun's experience shows that voluntary work (or 'helping out') can sometimes be an effective route into paid employment.

While some people say that they are forced into voluntary work because they have been unable to secure paid employment, Shaun's experience highlights that learning disability organisations can help people make that step from voluntary work to paid employment and at the same time help to develop their skills, confidence and social networks.

## 6 The impact of getting a job

This session has shown that there are a number of barriers to people with learning disabilities getting the jobs they want. However, as Shaun's experiences highlighted in the previous section, finding a good job can make a big difference to their lives. Now complete Activity 7 which looks at another example of the positive impact work can have.

### Activity 7 Positive stories of work

Allow about 10 minutes

Watch this video of people with learning disabilities at work. Then answer the questions below.

Video content is not available in this format.

#### Video 6



1. What can an employer do to support people with learning disabilities into work?

*Provide your answer...*

#### Discussion

Some of the things you may have picked up from the film include: offering working interviews; providing training; having a positive attitude towards learning disability; looking at the overall picture to see which jobs might suit a person with a learning disability; not pre-judging someone's ability.

2. What are the benefits to the employer?



*Provide your answer...*

#### Discussion

These include the potential to employ hardworking, reliable and loyal employees. Employing people with learning disabilities can also give a positive impression and show that the organisation is inclusive.

3. What are the benefits to the employee?

*Provide your answer...*

#### Discussion

In the film, some people commented that getting a job they liked had changed their life. It can provide enjoyment, a sense of satisfaction and a way to make new relationships.

The film shows that there can be many benefits to individuals and employers when people with learning disabilities are given the opportunity to work. One contributor to the video you have just watched emphasised to employers that they shouldn't be afraid and mustn't put up barriers. Films like this are important to show positive examples of where things are working well, and why.

## 7 This session's quiz

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Well done – you have reached the end of Session 5. You can now check what you've learned this session by taking the end-of-session quiz.

[Session 5 quiz](#)

Open the quiz in a new tab or window by holding down Ctrl (or Cmd on a Mac) when you click on the link. Return here when you have finished.

## 8 Summary of Session 5

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This session has shown you that while many people with learning disabilities want to work, there are a number of barriers that can make this hard to achieve. People with learning disabilities have a lot to offer employers but they need to be given opportunities and support to fulfill their potential.

You have learned about examples of inclusive workplaces where people with learning disabilities are part of the team and are able to develop their confidence and skills. But you have also heard some of negative experiences, where employers' expectations of people with learning disabilities were low, and the work available was poor.

It is important that more people with learning disabilities are given opportunities to do work if they want to – either in a paid or voluntary capacity. But this work needs to be meaningful and positive, in environments that are inclusive, respectful and supportive.

This session you explored:

- what helps people with learning disabilities get and keep a job
- what makes it more difficult for people with learning disabilities to get and keep a job
- what is good or bad work for people with learning disabilities.

You can now go to [Session 6](#).

## Want to know more?

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- The NDTi have produced a lot of resources to help support more people with learning disabilities into work: <https://www.ndti.org.uk/our-work/our-projects/employment1/>
- You can also find out more about employment for those with learning disabilities through Mencap:  
<https://www.mencap.org.uk/about-us/what-we-think/employment-what-we-think>



# Session 6: Health and wellbeing

## Introduction

In this session you will consider the health and wellbeing of people with learning disabilities.

Video content is not available in this format.

### Video 1



As you learned in Session 1, a learning disability is not, in itself, an illness. The definition is dictated by people's need for support in managing their lives successfully. But people with a learning disability *do* face particular challenges when it comes to health and wellbeing.

Statistics show that people with learning disabilities die on average more than 20 years earlier than the population of the UK (University of Bristol, 2018). Rates of obesity are also higher than average (Heslop et al., 2013) as it can be difficult for people to understand messages about healthy eating and exercise, and why they matter. Many people also have additional health problems such as epilepsy or diabetes, cerebral palsy or swallowing difficulties.

Despite all this, people often struggle to get good quality healthcare, even in the NHS.

In this session you will explore:

- situations where making independent choices may conflict with a healthy diet and lifestyle
- changes that can enable people to receive improved healthcare
- ongoing weaknesses in delivering good healthcare and how failures have resulted in serious harm and preventable deaths
- how health risks can be reduced if well managed
- why people with learning disabilities can be vulnerable to loneliness.

# 1 What are some of the health risks?

People with learning disabilities make up about 2% of the global population. However, as you saw in Session 1, only a quarter of adults with learning disabilities are identified in English GP learning disability registers and are known to specialist learning disability services.



**Figure 1** People with learning disabilities can face a number of additional health challenges

This is a big concern because people with learning disabilities:

- are likely to be at risk from the determinants of health inequalities, like poverty and poor education
- are more likely to live with multiple health conditions
- are at increased risk of early (and avoidable) death – latest reports show average age of death at 58 (University of Bristol, 2018)
- often have limited access to health information because of communication difficulties, low expectations, lack of support, poor understanding of mental capacity and lack of reasonable adjustments by health services
- often rely on others, such as family carers or support workers, for help with access to healthcare; access can be poor if those people are not well informed themselves or there is a high turnover of workers
- are entitled to an Annual Health Check and health action plan if aged 14 or over and they are on their GPs' learning disability registers. However, in 2014 to 2015 just under 50% of those on registers had a health check (Public Health England, 2016).

People with learning disabilities face striking inequalities when it comes to their health. In the following sections you'll learn more about why this is the case.



## 2 As independent as possible?

Independence is a goal for many people with learning disabilities, and it is also a stated government policy. But what does 'independence' actually mean? And how do you balance independence with sensible and healthy choices?

### Activity 1 Leah and Sheila: choice vs health

Allow about 20 minutes

First read the account from Sheila, whose daughter, Leah, has mild learning difficulties. This is Sheila's perspective. Then, based on what you have read, write down what you think Leah and her support worker's perspectives on the situation would be. Write down one sentence for each.

#### LEAH: AS INDEPENDENT AS POSSIBLE?

My daughter Leah is as independent as possible.

She maintains (with paid support) her own tenancy in the town where she wants to live, has a long-term relationship with a partner, has a small but important group of friends who mean a lot to her. She volunteers at two places where her help is welcome. She maintains close links with her family and family friends. She can travel on her own on familiar journeys. These are markers of independence which many people who have a learning disability would love.

Much of this has been gained through her own efforts and personal qualities. Yet to maintain this level of independence Leah needs the efforts of her immediate family. Because she lives as independently as possible the contributions we make are almost invisible. The visible bits are her social work assessments and reviews, her social care support hours and her small Direct Payment. But the bits we, her family, add are the bits which add richness, depth and joy. These are the 'added value' provided by her family.

I've watched with concern as my previously fit, healthy, slim daughter has gained several stone in weight, lost fitness, core body strength and suppleness at a young age. I know that Leah's diet is harming her health in the short and longer terms. I also know that raising this concern with the people who provide her support will be seen as interfering. They have a case. Leah has capacity, some understanding of the health concerns and it could be said that she is making an informed choice, in the knowledge of the risks, to eat unhealthily and take little exercise.

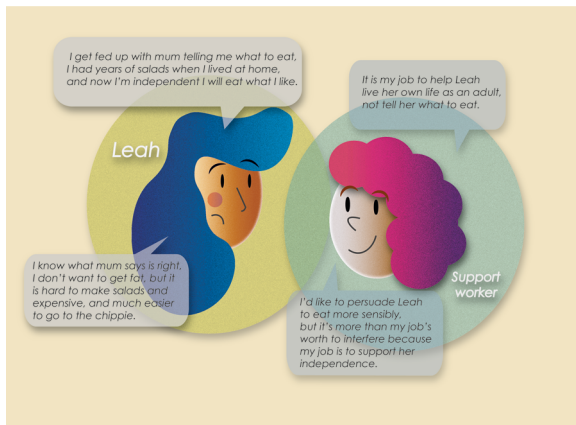
The support of family carers can be, and often is, seen as interference and over-protection. At reviews of Leah's support, I mention my concerns about her diet and heads nod. That's as far as it goes.

Independence of the sort which Leah has achieved comes with privileges and risks. Leah exercises the privilege of choice in relation to her diet and lifestyle. In doing so she runs the risk of compromising her health. For a parent carer this is a tension which has no clear resolution.

Provide your answer...

### Answer

There are many different ways you could approach this. Here are two examples from each perspective.



**Figure 2** Differing perspectives on keeping healthy

Did these reflect what you wrote?

As discussed in Session 3, in relation to how Dora dresses, independence and choice are great, but the devil lies in the detail. Translating them into action can be hard. You will explore this further next – with diet again the focus.

## 2.1 The right to choose

How do you support someone to make healthier choices, while respecting their right to make their own decisions?

### Activity 2 The cheese sandwich

Allow about 5 minutes

Jimmy lives by himself. He has help from a support worker to prepare his evening meal. When Jimmy's parents visit, she tells them Jimmy will only eat cheese sandwiches for dinner. His parents are anxious about this as it is not a healthy diet. But the support worker believes it is Jimmy's right to choose.



**Figure 3** Staff may find themselves balancing different priorities when supporting people

Which of the following might help a support worker resolve this issue while still respecting Jimmy's right to choose?

- ☐ 1. Find out what Jimmy is eating the rest of the day to build up a picture of his overall diet
- ☐ 2. Check that Jimmy understands what his choices are
- ☐ 3. Encourage Jimmy to have a tomato or some coleslaw with the sandwich
- ☐ 4. Find out how his family have encouraged Jimmy to vary his diet in the past
- ☐ 5. Take over cooking Jimmy's meals
- ☐ 6. Find out if Jimmy needs more help with shopping or learning how to cook
- ☐ 7. Find out if Jimmy is choosing a simple quick meal because his favourite TV programme is on at the time
- ☐ 8. Tell Jimmy he can only have a cheese sandwich three times a week

**Answer**

All but 5 and 8 are actions you could take while respecting Jimmy's rights to choose.

In this activity you explored some of the issues in making positive lifestyle choices, while respecting people's rights as adults to make choices. Balancing respect for people's right to choose with encouragement to make healthy choices will never be easy, and requires empathy and imagination.

In the next section you will explore the quality of healthcare for people with learning disabilities.

## 3 Healthcare

One reason Leah and Jimmy's parents might be worried about their adult children is that healthcare for people with learning disabilities is often poor.

In recent years, there has been a series of official reports and investigations into healthcare for those with learning disabilities. The outcomes of the reports have revealed some positives, including:

- Life expectancy has increased dramatically since c. 1950. Then, people with Downs Syndrome, like Bernie Lee from previous sessions, could not expect to live beyond their fifth birthday. Now 48% of people with Downs live to see their 50th birthday – and Bernie has far surpassed this, reaching 68 as of the time of writing (2019).
- Many more children with severe and complex needs are reaching adulthood (Public Health England, 2016).
- Free annual health checks with GPs have been offered to adults in England since 2008. Annual health checks have also been available in Wales since 2006 and in Northern Ireland since 2011.
- Like other providers of services, GPs and hospitals are legally obliged to make 'reasonable adjustments' to ensure that people with learning disabilities get equal access to healthcare.

Despite these positives, there has also been heavy criticism of mainstream healthcare for those with learning disabilities. For example, the 2007 Mencap report *Death by Indifference* showed some people dying because of poor hospital care, while a government report in 2008 said some NHS care for those with learning disabilities was 'appalling'. Then, in 2012, Mencap released another report, *Death by Indifference: 74 deaths and counting*, which concluded that standards were still not being met.

For a summary of the key reports into the inequalities in healthcare from 2001 onwards click on the link below (You should open the link in a new tab by holding down Ctrl (or Cmd on a Mac) when you click on the link.). Note this is optional and you will not be quizzed on the content in this link. You will review the conclusions and recommendations of the reports in the next section.

[Link: Reports on inequalities in healthcare.](#)

### 3.1 The shortcomings of healthcare

The conclusions of the many reports into the shortcomings of healthcare for people with learning disabilities echo one another. Their findings include:

- poor communication
- failure to listen to and learn from family and others who know the person well
- failure to adjust systems and communications methods to take account of poor literacy, lack of access to transport and other disadvantages experienced by people with learning disabilities
- need for documentation, such as a health passport, to accompany the person as they encounter healthcare
- need for more and improved training for all healthcare professionals.



**Figure 4** Mencap's *Death by Indifference* report (2007) showed that people with learning disabilities were dying early because of poor hospital care

Recommendations to deal with these now well recognised problems include the following measures:

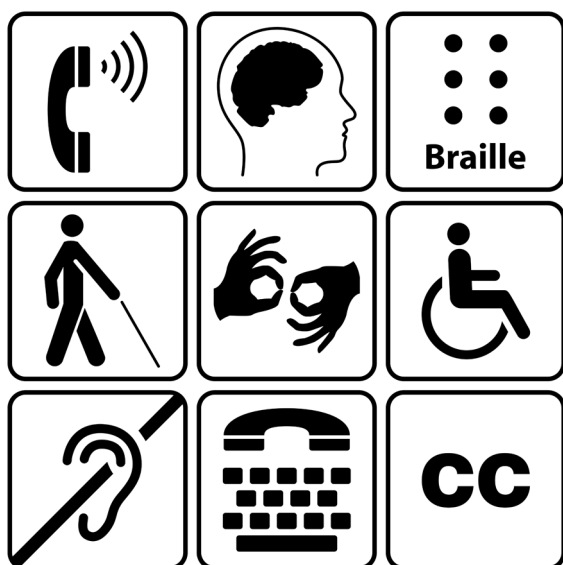
- introducing 'health navigators', people who have the job of helping someone with very complex needs to 'navigate' the health and care system
- using liaison nurses in hospitals whose job it is to support other staff when treating someone with a learning disability

- the use of health passports explaining the person's health conditions, their likes and dislikes, and their preferred methods of communication
- more and improved training for all healthcare professionals
- involving the patient's family/people who know them well in their care and treatment
- making adjustments, such as longer appointment times, phone calls instead of letters, appointments at quiet times, etc. to suit the needs of people with learning disabilities.

Some of these ideas have been translated into legislation, known as 'reasonable adjustments', to promote equality of access.

## 4 Reasonable adjustments

Like other organisational bodies, health services must by law make 'reasonable adjustments' to make sure people with disabilities, including learning disabilities, can access high quality healthcare. In the next activity you will explore what this might actually mean in practice.



**Figure 5** Reasonable adjustments are now underpinned by the law

### Activity 3 What are reasonable adjustments?

Allow about 20 minutes

The Royal College of Nursing (RCN) has outlined the sort of adjustments that should be made for people with learning disabilities if their disadvantages in accessing good quality healthcare are to be addressed.

Reasonable adjustments can be made to many areas of health services. Services can ensure, for example, that:

- buildings, including toilets, are accessible to people with physical disabilities
- signposting is clear and easy to follow
- information and advice is offered in formats and languages that people can understand
- extra time is offered to people who have particular communication needs or difficulty understanding what is being said
- alternatives to hospital or clinic attendance are considered for those who have problems in getting to appointments
- families and friends of people with disabilities are actively involved, if the person wishes them to be.

(The Royal College of Nursing, 2015)



Now read Jessica's story below from the *Confidential enquiry into premature deaths of people with learning disabilities* (Heslop et al., 2013) and then answer the question that follows.

### Case study – Jessica

Jessica had surgery for congenital heart disease at the age of four. She had biannual follow-ups from the paediatric congenital heart disease team throughout her childhood. She was expected to be reviewed again by the adult congenital heart disease team three years after moving from paediatric to adult services, but this did not happen. She was later discharged from the clinic as being 'lost to follow-up'. Jessica had little contact with health services, and did not receive Annual Health Checks from her GP. She subsequently died from complications of her heart disease, and the panel reviewing the circumstances of her death identified the lack of follow-up for her heart disease as being a contributory factor in her premature death.

(Source: Heslop et al., 2013)

What 'reasonable adjustments' might have made a difference to Jessica?

Provide your answer...

### Answer

Taken one by one, no single adjustment listed by the RCN would have been enough by itself to prolong Jessica's life. Improved communication and a readiness to administer treatment other than in the most routine of ways would have helped.

What also appears to be missing here was anyone to check that what the paediatric team had prescribed was actually happening. A 'reasonable adjustment' might have been for the clinic to ask a Learning Disability nurse to visit Jessica to find out why she had not come to clinic, and to understand what might have prevented her going.

At the same time, Jessica's GP could have taken proactive steps to invite her for an annual check-up, to which she was entitled.

You can see from this example that 'reasonable adjustments' have to be more than a tick-box exercise. They require someone with authority to pay attention and take action. In the next section you will look at other examples of unnecessary deaths which help to reinforce this message.

## 5 Unnecessary deaths

A sense of urgency has been lent to the efforts of addressing the healthcare needs of people with learning disabilities by some high-profile cases where young people have needlessly died.



**Figure 6** A clearer picture of the numbers of people with learning disabilities who have needlessly died while in hospital is being built

In the next activity you will explore the case of Richard Handley, who had Down's syndrome and suffered lifelong constipation.

### Activity 4 The case of Richard Handley

Allow about 30 minutes

Read the article from *The Guardian* at the link below. Then answer the questions that follow.

[Link: 'Gross failure' in man's care led to death from constipation](#)

1. How might 'reasonable adjustments' have made a difference to Richard?

Provide your answer...

2. What else would need to happen to prevent these 'gross failings'?

Provide your answer...

### Answer

The enormity of what happened to Richard makes it hard to easily unpick how it could have been prevented. However, one of the main issues picked up by the series of reports on healthcare was that no single person has an overview of the complex systems and sets of relationships involved in the care of a person with complex impairments and health needs. Families may try to do this, but they lack the knowledge of the interlocking systems, and, crucially, the authority to command action from healthcare professionals.

Families can be immensely helpful. They can sit with the patient, interpret their communication, explain resistance to blood tests or other interventions, and just be a reassurance in an unfamiliar environment. Sometimes their help is welcomed, but sometimes it can be branded as 'interfering', as Sheila put it in the scenario in [Section 2](#) of this session.

Health passports can be useful – as long as they are up to date and everyone knows about them *and* remembers to consult them.

## 6 When things go well

Sometimes 'reasonable adjustments' can make a huge difference. Read the examples below of how 'reasonable adjustments' have benefited William, Margaret and Mary.

### William

William was diagnosed with coeliac disease. His dietician found out where he liked to buy his food, and went there to take photos of the foods it was OK for him to eat. She used the photos to prepare a laminated sheet for him to take shopping.

### Margaret

Margaret's GP noticed that she was calmer when her key worker was with her. He asked the receptionist to find out when the key worker was on duty before making the appointment for her Annual Health Check.

### Mary

Mary's learning disability nurse visited her before she went into hospital, to tell her what would happen and find out how she liked to be supported. The nurse then shared this information with the ward staff. She visited Mary during her stay to find out how things were going.

(Source: adapted from Heslop et al., 2013)



**Figure 7** Often it's attention to the small things that can have a big impact on the quality of a person's healthcare

There is a long way to go before it is possible to be confident that people with learning disabilities are no longer disadvantaged in accessing high quality healthcare. But a start has been made – we know there is a problem and we know what needs to be done.

## 7 Isolation, loneliness and ill health

Isolation and loneliness have been identified as particularly acute for people with learning disabilities. Reports, such as those undertaken by Mencap (no date), have consistently said that many people with learning disabilities have few friends or close relationships, and often rely on family or paid staff for companionship. This can affect people's health and wellbeing.

Ironically, some of the changes made to support independence and choice have made loneliness more acute. Closing the sorts of day centres which Bernie Lee attended for much of her adult life in favour of people joining in mainstream social activities can mean that people do not have regular companionship. Living on your own, with support, is great, but the trade-off can be loneliness. This is what one tenant said to a researcher:

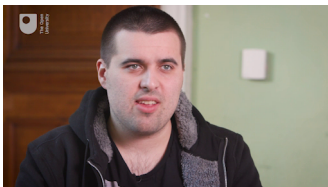
I do get lonely. I don't want anyone else in the house because it would be another resident and then I'd have to have the staff for them and it wouldn't be a home and I don't want that.

(Source: unpublished research project conducted by author, 2011)

Now listen to Cian, who you first met earlier in the course, talk about the impact loneliness, and having nothing to do, had on his health when he was younger.

Video content is not available in this format.

### Video 2



Did you notice what Cian said about his mental health? That people thought it was just part of his autism. This is known as 'diagnostic overshadowing', an assumption that a health problem is caused by the learning disability – when in fact it is nothing to do with it.

### 7.1 Improving health and wellbeing

In the next video, Cian explains how he overcame his mental ill health and overeating.

Video content is not available in this format.

### Video 3



Cian explained that things changed for him when he discovered Access All Areas, a drama group for people with learning disabilities and autism. It is perhaps a paradox that at a time when inclusion is viewed as so important, organisations specifically for people with learning disabilities and their families are necessary.

### Activity 5 Pedal Power an organisation for people with learning disabilities and their families

Allow about 20 minutes

Some people believe that special activities for people with learning disabilities and their families are part of a discredited past, when people with learning disabilities were shut away. Watch this video about Pedal Power, a social activity for people with learning disabilities and their families. Then respond to the poll at the link that follows.

Video content is not available in this format.

#### Video 4



[Link: Specialist organisations](#)

Once you have submitted your choice you can then see how others have voted.

Segregated or special services and activities remain controversial, but there is plenty of evidence that in a world where not everyone is equal, organisations and events specifically for people with learning disabilities have an important part to play in promoting a sense of wellbeing and combatting loneliness.



## 8 This session's quiz

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Well done – you have reached the end of Session 6. You can now check what you've learned this session by taking the end-of-session quiz.

[Session 6 quiz](#)

Open the quiz in a new tab or window by holding down Ctrl (or Cmd on a Mac) when you click on the link. Return here when you have finished.



## 9 Summary of Session 6

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In this session, you have considered issues around health and wellbeing for people with learning disabilities. While a learning disability is not itself an illness, it is often accompanied by health conditions like epilepsy or cerebral palsy. People with learning disabilities are also vulnerable to ill health because of lifestyle issues, such as diet or lack of exercise, and this is exacerbated by poverty, isolation, loneliness and poor education. To ensure equal treatment, services need to make a special effort to adjust for the needs of people with learning disabilities. A great deal can be done to mitigate the risks people with learning disabilities face, but it requires training and a willingness to involve carers, paid or unpaid, in their care and treatment. The laws are in place for this – the problem is well known, but practice often lags behind.

In this session you explored:

- situations where making independent choices may conflict with a healthy diet and lifestyle
- changes that can enable people to receive improved healthcare
- ongoing weaknesses in delivering good healthcare and how failures have resulted in serious harm and preventable deaths
- how health risks can be reduced if well managed
- why people with learning disabilities can be vulnerable to loneliness.

You can now go to [Session 7](#).

## Want to know more?

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- Mencap's Report on friendship and loneliness is available from this link:  
<https://www.mencap.org.uk/learning-disability-explained/research-and-statistics/friendships>
- Sara Ryan's book *Justice for Laughing Boy* (2018) is an account of the death in an NHS Unit of her son, Connor Sparrowhawk, aged 18, and his family's quest for justice.
- The National Development Team for Inclusion website has resources and information about reasonable adjustments, reports, and other initiatives to address health needs: <https://www.ndti.org.uk/resources/>
- The most recent research into health inequalities and learning disabilities in the UK was published in 2011:  
<https://webarchive.nationalarchives.gov.uk/20160704145749/http://www.improvinghealthandlives.org.uk/projects/particularhealthproblems>



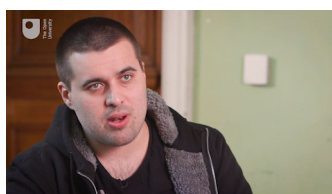
# Session 7: Relationships

## Introduction

Good relationships enrich people's lives. They help you feel like you belong. Most people value having good relationships as it is important to be able to share your interests, worries, stories and experiences with others who know and understand you. This applies to people with learning disabilities too. However, it is not always easy for people with learning disabilities to develop and sustain the relationships they want.

Video content is not available in this format.

### Video 1



In this session you will explore:

- how people with learning disabilities can be involved in caring relationships
- the importance of friendship for people with learning disabilities
- barriers to people with learning disabilities developing romantic and sexual relationships
- how people can be supported to avoid abusive relationships.

## 1 Caring relationships

It is known that people with learning disabilities need support from other people. But what may surprise you is that people with learning disabilities can also be carers, providing support to their friends, partners, parents and children.

### Activity 1 Relationships in the institutions

Allow about 10 minutes

Watch this film about Gloria Ferris and Muriel Mussett. Gloria and Muriel met when they both lived in St Lawrence's institution and their relationship continued when they moved into the community. Afterwards fill in the table below.

Video content is not available in this format.

### Video 2



**Table 1 Gloria and Muriel's relationship**

Terms that Gloria uses to describe her relationship with Muriel	Tasks that Gloria helped Muriel with	Things that made Gloria and Muriel's relationship difficult after Muriel left the institution
<i>Provide your answer...</i>	<i>Provide your answer...</i>	<i>Provide your answer...</i>

## Discussion

**Table 1 Gloria and Muriel's relationship (completed)**

Terms that Gloria uses to describe her relationship with Muriel	Tasks that Gloria helped Muriel with	Things that made Gloria and Muriel's relationship difficult after Muriel left the institution
<ul style="list-style-type: none"> <li>• mother</li> <li>• advocate</li> <li>• friend</li> </ul>	<ul style="list-style-type: none"> <li>• washing</li> <li>• feeding</li> <li>• dressing</li> </ul>	<ul style="list-style-type: none"> <li>• Muriel lives far away</li> <li>• the transport links aren't very good</li> <li>• they don't see each other as often as Gloria would like.</li> </ul>

The one term that Gloria doesn't use to describe her relationship with Muriel is that of 'carer'. This is despite the fact that Gloria was very involved in Muriel's care in the institution – and after. You may have been surprised to learn that people like Gloria had caring roles in the institutions. However, it has been argued that institutions were only economically viable because some people with mild or moderate learning disabilities did unpaid work when they lived there.

Watching the video you can see that Gloria didn't resent taking on this role of 'carer' – indeed she was very happy to care for Muriel in this way. But the film also shows that the relationship between them was not only about caring. Gloria says 'it's both ways', suggesting that the two women became good friends. Gloria also talks about being 'like a mother' to Muriel, suggesting their relationship was deeply felt.

While most people with learning disabilities were very happy about being moved into the community, it did present difficulties for friendships. Gloria and Muriel spent much less time together after leaving St Lawrence's. Very sadly, other people completely lost touch with their friends after leaving the institutions.

## 1.1 Caring in intimate relationships

Like others in the population, some people with learning disabilities find themselves becoming a carer for their partner.

### Activity 2 Shifting roles

Allow about 10 minutes

Watch this short video about Charlene and Terry. They are in a romantic relationship but Charlene is also Terry's carer. Then answer the questions below.

Video content is not available in this format.

### Video 3



1. Why has Charlene taken on more responsibility for Terry's care?
  - Because Terry's social care package changed
  - Because Terry's family circumstances changed
2. What are some of the things that Charlene supports Terry with?
  - Getting ready to go somewhere
  - Getting to places
  - Financial issues

Have the videos about Charlene and Terry (Video 3) and Gloria and Muriel (Video 2) in this section challenged your views about the types of relationships that people with learning disabilities have? The boundaries in relationships are often blurred: a romantic relationship may cross into a caring relationship; a caring relationship may become a deep and long-lasting friendship. This applies to everyone, not just people with learning disabilities.

This section has shown that while many people with learning disabilities need support, some also provide care and support for others. However, society rarely acknowledges when people with learning disabilities are caring for others. This means that people with learning disabilities can lose out on support or resources that they are entitled to as carers.

## 1.2 Parents with learning disabilities

Eugenics (see Session 2) had a big influence on how people with learning disabilities were treated in the past. Fears about people with learning disabilities having children led to people being segregated in institutions, and sometimes sterilised without their consent (Tilley et al., 2012).



**Figure 1** People with learning disabilities can, and do, parent

Today, people with learning disabilities can and do have children. But they are often discouraged from doing so. People with learning disabilities are also over-represented in the Child Protection system in many countries (Tarleton, 2015).

People with learning disabilities face a lot of barriers to being the best parents they can, often based on little more than other people's negative expectations about their abilities. But research has also shown that with tailored support in place, people with learning disabilities can and do parent effectively (Tarleton, 2015). While children's needs and welfare are paramount, 'parenting with support' can lead to positive benefits for both parents with learning disabilities and their children.

### Activity 3 A parenting story

Allow about 10 minutes

Read this real life case study about Maggi and David in the link below then answer the question that follows. (You should open the link in a new tab by holding down Ctrl (or Cmd on a Mac) when you click on the link.)

[Link: Maggi and David's story](#)

Select from the list below the factors that helped Maggi and David keep their family together after Anne was born:

- ☐ Early support from KeyRing
- ☐ Ongoing involvement from Flying Start
- ☐ Negative attitudes from some professionals
- ☐ Clear explanations to Maggi and David about what was expected of them
- ☐ A supportive and encouraging midwife and health visitor
- ☐ Support from their wider family
- ☐ Offensive comments from one social worker
- ☐ A belief that they could be good parents with the right support

This interview was recorded in 2009. Ten years on, in 2019, Maggi was interviewed again. She revealed that Anne is now approaching secondary school age and she and David have another child, Edward, who is 7. The family have moved to a new home. Maggi has also recently been diagnosed with dyspraxia, a developmental disorder that affects physical co-ordination. She no longer considers herself to have a learning disability



because recent assessments have shown her IQ is higher than professionals previously understood. Maggie thinks a lot of the difficulties she experienced in her earlier life were due to her own upbringing and her undiagnosed dyspraxia.

Looking back to when Anne was a baby, Maggi can appreciate she received some useful support, but also thinks that being labelled 'learning disabled' led a lot of professionals to make unfair assumptions about what she could and couldn't do. David does have learning disabilities, and Maggi supports him when he needs help. She also said she thinks that parents with any disability need more understanding and her message to professionals is: 'Do not judge until you've walked a mile in someone's shoes.'

## 2 Making friends

Friendships are good for everyone. As you learned in Session 6, friendships help to reduce loneliness and isolation. Reducing loneliness can improve people's physical and mental wellbeing, and can even lead to people living longer.

Having friends can also help people with learning disabilities feel more confident and be more independent, so it's vitally important. But does this reflect what is happening in people's lives?

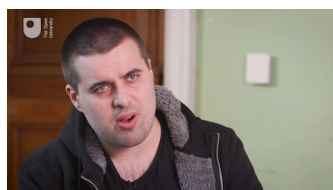
### Activity 4 Experiences of friendships

Allow about 10 minutes

Watch this video of Cian, Charlene and Terry talking about their friends. As you watch, note down anything that struck you as interesting or important in the video in the text box below.

Video content is not available in this format.

#### Video 4



*Provide your answer...*

#### Answer

You may have noted that Cian said he found it hard to make friends at school. He also said that sometimes his autism can make it more difficult for him to know who his 'real friends' are. Charlene said she has lots of good friends these days, but it can be hard finding the time to see them. Terry said that he had made good friends at Access all Areas. This includes other actors with learning disabilities, as well as the teachers. He said his friends were like family.

Video 4 shows that people make friends in a range of different contexts. It is not always easy for people with learning disabilities to make and keep friends, however. Practical issues like needing to travel to see your friends can also be a barrier for some.

It is also important that those who provide support to people with learning disabilities recognise the importance of friendships. This isn't always the case and sometimes support workers don't focus on what is needed to help people to make and sustain friendships.

## 2.1 Supporting people to have friends

Figure 2 shows Johanna de Haas with her friends Gloria and Steph. You may recognise Gloria from Video 2 earlier in this session. Gloria and Johanna met at an Open University conference a few years ago and struck up a long-lasting friendship.



**Figure 2** Johanna (centre) with her good friends Gloria (left) and Steph (right)

Johanna's family provided lots of opportunities for her to develop and maintain relationships. Here is Johanna's mother Catherine reflecting on Johanna's life:

Everyone has something to give whether they have disabilities or not. Everyone has something to gain from spending time with other people. I have been very privileged in my lifetime. I had a daughter with profound and complex learning disabilities. She never learned to talk, but she could make deep connections with other people. I learned so much from watching her with her friends. Like anybody else she made friends by participating in activities that were enjoyable such as singing together. She maintained her friends just like other people by doing things like going for a coffee or a meal. Towards the end of her life she could not eat, but she still enjoyed being in a cafe with other people. She loved to hear gossip, but has taken many secrets to her grave. She had a winning smile and a wicked sense of humour. Many people felt more comfortable with themselves after spending time in her company.

Catherine's words show that all people with learning disabilities can have fulfilling friendships. What Catherine describes here is not complicated – going for a coffee, a meal, or joining in a choir. Hanging out together. But Johanna needed someone to help facilitate these things for her. For many people with learning disabilities, the biggest barrier they face is not having the support they need to get out and about with their friends.

## 3 Romantic relationships

Research has shown that many people with learning disabilities want to have romantic and sexual relationships. People's right to do so is supported by law and policy. And yet it can be incredibly difficult for people to develop and sustain the types of loving relationships they want.

### Activity 5 Living together

Allow about 5 minutes

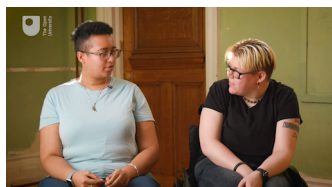
70% of the general adult population live as a couple. What percentage of people with learning disabilities do you think live as a couple?

- ☐ a) 3%
- ☐ b) 13%
- ☐ c) 30%

Earlier in this session you heard from Terry and Charlene who are in a long-term relationship. In the next video you will hear them talk about why they think their relationship has been successful and lasted for a decade.

Video content is not available in this format.

### Video 5



Charlene says they want to show people that they can cope, and that she and Terry can manage the usual ups and downs of a relationship. Although Charlene has taken on more responsibility for Terry's physical care of late, it's clear that Terry supports Charlene too. Terry suggests their relationship has been strengthened by the fact that they have many shared interests and friends. They also work for the same company, which means they can spend a lot of time together.

### 3.1 Barriers to loving relationships

Charlene and Terry's relationship shows that people with learning disabilities can and do have positive, supportive and long-term relationships. Lots of people with learning disabilities want to date, or have sex, or be in a relationship, but the evidence suggests that it is difficult for them to achieve this.

### Activity 6 What makes it difficult to find love

Allow about 5 minutes

Can you think of two or more reasons why people with learning disabilities find it hard to develop romantic or sexual relationships?

*Provide your answer...*

#### Answer

One person answering this question said:

- I think attitudes are part of the problem. I'm not sure that everyone thinks people with learning disabilities are capable of being in a romantic relationship, or the idea of it makes them uncomfortable.
- People with learning disabilities don't get many opportunities to meet potential boyfriends or girlfriends. People are socially isolated. That's a big problem.
- Services and families might feel nervous about this. Maybe they haven't had training or are worried about legal issues.
- Perhaps there are fears that it might result in pregnancy?

A report by the National Development Team for Inclusion (NDTi) (Harflett and Turner, 2016) highlighted some of the key barriers to people with learning disabilities enjoying romantic or sexual relationships. These are shown in Slideshow 1.

Interactive content is not available in this format.

[Slideshow 1](#)

Now watch Video 6 from the Tizard Centre at the University of Kent. Their research explored what support people with learning disabilities need in order to have loving relationships. In this video you will listen to people involved in the project talk about what they found out.

Video content is not available in this format.

[Video 6](#)



As you heard, the support people need to have relationships is often quite simple – for example, help to arrange a date; transport to get to places; and support to keep in touch. Unfortunately, lots of people with learning disabilities are not getting access to such support.

## 3.2 The importance of loving relationships

Why is it important for people to have a loving relationship? In the next activity, you will hear from some people with learning disabilities about why it matters to them.

### Activity 7 Valentine's day

Allow about 10 minutes

Watch this video about romantic relationships by self-advocacy group My Life My Choice then answer the questions that follow.

Video content is not available in this format.

**Video 7**



1. According to the people in the film, what are the benefits of being in a relationship?

*Provide your answer...*

#### Answer

According to the people in the film, the benefits of being in a romantic relationship include making you feel happy and wanted 'and a part of something'. Relationships also help you to feel supported. It's about having a companion and having someone to do nice things with, and someone to share your interests with.

2. What do they say are the downsides to being on your own?

*Provide your answer...*

#### Answer

The people in the film said that not being in a relationship can make you sad. It can make you feel lonely.

People with learning disabilities have a right to family life. They want their sexuality and sexual lives to be respected. It's important that people with learning disabilities get equal access to good sex education and relationship advice. But it's also important that the people who support them access good guidance and training too.



## 4 Managing the risks – avoiding harmful relationships

When asked what really matters in their lives, people with learning disabilities say that love, relationships and having friends are all important. But people with learning disabilities are sometimes prevented from developing relationships because of fears about their safety. Family and support workers may be concerned that the person is vulnerable and may worry that a relationship puts them at risk. Sometimes family members feel embarrassed talking to people about sex and relationships; at times staff may worry that they will be blamed if things go wrong (Choice Support, 2019).

Listen to this short clip of support workers discussing some of the challenges of helping people to be in loving relationships.

Video content is not available in this format.

### Video 8



One support worker talked about ‘normalising’ the conversation about people with learning disabilities being in relationships. Another spoke of thinking about how it would feel to be in the shoes of the person with learning disabilities. One support worker emphasised that their job was about support and not control. They all identified the need for better training to help support workers understand their role when it comes to relationships.



## 4.1 Hate and mate crime

It is understandable that staff and families have concerns about relationships for people with learning disabilities particularly because people with learning disabilities experience higher levels of 'hate crime' and 'mate crime' than the general population.



**Figure 3** People with learning disabilities are more at risk of hate and mate crime than others

### Box 1 Defining hate crime and mate crime

**HATE CRIME:** This is when people are targeted purely because of their learning disability.

**MATE CRIME:** This is when people are abused and exploited by someone they know. This might include emotional, physical or financial abuse. Sometimes this has tragic consequences – for example, the case of Gemma Hayter, who was murdered by people she considered to be her friends (Day, 2019).

Research is also beginning to reveal the severity and frequency of domestic violence that some women with learning disabilities experience (McCarthy et al., 2017). These are very serious issues. Support workers view their role as 'a juggling act', trying to strike the right balance between helping people to have good relationships, and protecting them from bad ones (Maguire et al., 2019).

## 4.2 Safeguarding

Keeping people safe – sometimes described as 'safeguarding' – is an important part of a professional's job. Parents of people with learning disabilities also report the dilemmas they face in supporting their adult children to take risks, while wanting to protect them from harm.

It is a difficult balancing act. Under the law, people with learning disabilities in the UK can make 'unwise decisions' if they have capacity (Scotland. *Adults with Incapacity (Scotland) Act 2000*; England and Wales. *Mental Capacity Act (England, Wales), 2005*; Northern Ireland. *Mental Capacity Act (Northern Ireland) 2016*). This can include decisions about relationships. But if someone supporting a person with learning disabilities is concerned that the relationship is putting the individual in danger, how can this dilemma then be resolved?



**Figure 4** Empowering people while keeping them safe can be a difficult balancing act

The Local Government Association has developed a policy called 'Making Safeguarding Personal' (Lawson, 2017). This is about supporting people with learning disabilities to take positive risks, while safeguarding their own wellbeing, wherever possible. It doesn't mean the risk of abuse goes away, but it is an approach that is based upon human rights and focuses on empowering people to make informed decisions.

### Activity 8 Practical steps to manage risk

Allow about 10 minutes

Can you think of at least three ways in which people with learning disabilities can be supported to take positive risks in their relationships?

*Provide your answer...*

#### Answer

Here are some ideas you may have come up with:

- Helping people to recognise their right to be safe
- Helping people to understand when a relationship might be abusive
- Making sure people with learning disabilities know who to speak to if they have concerns about a relationship (for example, a trusted supporter or advocate)
- Giving people information about where they can go for help, if they need it
- Providing people with clear and accessible information about sex and relationships
- Providing sex and relationships training to supporters, including staff and family.

Loving relationships are important to most people. People with learning disabilities have the same rights as others to be in relationships. But family members, supporters and professionals must also be alert to when people are at risk of abuse. It is important that people with learning disabilities are given the support, information and advice they need to make informed decisions about their relationships.

## 5 This session's quiz

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Well done – you have reached the end of Session 7. You can now check what you've learned this session by taking the end-of-session quiz.

[Session 7 quiz](#)

Open the quiz in a new tab or window by holding down Ctrl (or Cmd on a Mac) when you click on the link. Return here when you have finished.

## 6 Summary of Session 7

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Relationships matter to people with learning disabilities. Good relationships help people to feel valued, connected, happy and healthy. People with learning disabilities sometimes need extra support to enable them to develop and keep good relationships. They may also need support to help them to avoid relationships that are harmful.

In this session you explored:

- how people with learning disabilities can be involved in caring relationships
- the importance of friendship for people with learning disabilities
- barriers to people with learning disabilities developing romantic and sexual relationships
- how people can be supported to avoid abusive relationships.

In the next and final session of this course, you will consider what is needed to help more people with learning disabilities feel like they belong in society.

You can now go to [Session 8](#).

## Want to know more?

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- Relationships, Sex and Sexuality, Easy Read Guide, by the Brandon Trust:  
[https://www.brandontrust.org/old\\_media/313124/brandon-trust-easy-read-relationships-sex-and-sexuality.pdf](https://www.brandontrust.org/old_media/313124/brandon-trust-easy-read-relationships-sex-and-sexuality.pdf)
- Mencap provide information about hate and mate crime:  
<https://www.mencap.org.uk/advice-and-support/bullying/mate-and-hate-crime>
- Working Together with Parents Network is a free network for professionals working with parents with learning disabilities and their children. The network provides professionals from a wide variety of backgrounds with up-to-date information on policy and practice as well as access to support from a regional group and email discussions. There are 4 regional practitioner networks England and national networks in Wales and Scotland: <http://www.bristol.ac.uk/sps/wtpn>
- The Supported Loving Project provides information from people with learning disabilities, their families and practitioners on how to support people to experience positive relationships:  
<https://www.choicesupport.org.uk/about-us/what-we-do/supported-loving>
- The Love Project (Tizard Centre, University of Kent) made a film entitled *Love is a Wonderful Feeling* based on their research about the support people with learning disabilities need to find loving relationships: <https://vimeo.com/332887161>. They also made a film about dating agencies for people with learning disabilities, entitled *Making Connections, Building Confidence*: <https://vimeo.com/336573029>



# Session 8: Making belonging happen: rights and advocacy

## Introduction

Video content is not available in this format.

### Video 1



The closure of the last of the institutions in the UK in 2009 was supposed to herald a new era for people with learning disabilities. The vision was that people would live ordinary lives – in the community – along with everyone else.

In Session 2 you learned about how the large institutions were finally closed. You heard Mabel Cooper saying that people should never have to go back into such places. And you learned how disabled activists were talking about the social model of disability, which led to a much greater focus on disabled people's rights.

But people with learning disabilities, their families and those who support them, are not always aware of their rights. Public sector bodies, services, organisations and companies might not take people's rights seriously. In the worst cases, people's rights are ignored or even violated. One of the key challenges is making sure there is a workforce that can support people's rights and enable them to feel like they belong.

In this session you will explore:

- why it has proved so hard for people with learning disabilities to have their rights upheld
- the role of self-advocacy and family advocacy in helping people to understand their rights and get their voices heard
- the role of the workforce in helping people to uphold their rights.

# 1 Upholding people's rights

People with learning disabilities are entitled to the same rights and freedoms as everyone else in society. As you learned in Session 1, this is enshrined in law across a number of countries – for example, the UK Human Rights Act 1998 and the UK Equality Act 2010. It is also backed up by an important international agreement called the United Nations Convention on the Rights of Persons with Disabilities (UNCRPD). But does this reflect the reality of people's day-to-day lives?

## Activity 1 Experiences of rights

Allow about 10 minutes

Watch this video of people with learning disabilities talking about rights then answer the questions that follow.

Video content is not available in this format.

### Video 2



1. Click the link below to answer the poll on rights.

[Link: Rights](#)

Once you have submitted your choice you can then see how others have voted.

2. Make a note of some of the things that stop people's rights being upheld, according to the people in the video.

*Provide your answer...*

### Answer

Some of the issues you may have noted are:

- there is not enough support or help available
- prejudice and stigma
- systems and processes that make people feel stressed
- people with learning disabilities being afraid to ask for help.

Video 2 showed that there are a number of barriers that stop people with learning disabilities exercising their rights. In the next section, you will read about the devastating impact this can have on people's lives.



## 1.1 Assessment and treatment units: the new institutions?

In 2018, the Rightful Lives online exhibition was launched in the UK, arguing that the rights of many people with learning disabilities were not being upheld. This included people who live in Assessment and Treatment Units (ATUs) or private facilities where people are sometimes locked away for years, with no say about what happens to them.

ATUs were brought to public attention in 2011 by a BBC *Panorama* programme that exposed the abuse happening in the Winterbourne View private hospital. This led to six members of staff going to prison, in recognition of the seriousness of their offences. The government then set up the Transforming Care programme to get people out of ATUs. But at the last count (2018) there were still over 2,300 people living in such units.

In 2019, *Panorama* broadcast a second programme which showed disturbingly similar abuse happening in another ATU – Whorlton Hall – eight years later.

The lack of suitable community-based services means that even when people are discharged, they often find themselves back in these private hospitals within a matter of weeks or months. On a range of counts, the situation facing many people with learning disabilities and autism in these units represents a fundamental breach of human rights.

### Activity 2 Eden's story

Allow about 10 minutes

1. Watch this video about Eden, who has autism and mild learning disabilities. After you have finished watching, note down your immediate reaction to the video.

Video content is not available in this format.

**Video 3**



Provide your answer...

#### Answer

One person who watched this video said:

I was utterly shocked by what Eden and his family have been through. How can this be happening to people in 21st-century Britain? Mistakes being made over and over again. No one listening to Eden and his family. The fact that Eden was moved so far from home, and then moved back without proper support in place. And the conditions in the units that his mum describes sound inhumane.

2. Complete the drag and drop activity below to identify the breaches of Eden's human rights that were described in the film:

Right to education (Article 2 Protocol 1)

Right not to be tortured or treated in an inhuman or degrading way (Article 3)

Right to liberty (Article 5)

Right to respect for private and family life, home and correspondence (Article 8)

Match each of the items above to an item below.

Eden left without a school place for two years

Eden put on high levels of anti-psychotic medication, denied opportunities to exercise, fed through a hatch, kept in a secluded room with no toilet

Kept in secure units for many years with no effective planning for his discharge home

Being placed hundreds of miles from his home and family

You may have found it shocking and distressing to hear about Eden's experiences. Sadly, his experience is not unique and there are many other people in similar situations. You can find out more on the [Rightful Lives](#) website.

In the next section you will explore how people with learning disabilities have learned to speak up for themselves and fight for their rights.

## 2 Self-advocacy and getting to know your rights

Exercising your rights is not always easy, especially for people with learning disabilities. This is because information about people's rights is not always made available to them in ways that are accessible. Sometimes information about rights is deliberately withheld from people to stop them asking difficult questions, or challenging things.

To exercise your rights, two things need to happen:

- you need to know what your rights are
- you need to feel confident or empowered to assert your rights.

Having the knowledge and confidence to talk about rights can be difficult for people with learning disabilities. This is where self-advocacy comes in. Self-advocacy is about speaking up for yourself. It is also about people with learning disabilities coming together to have more power and to make changes.

### Activity 3 The beginnings of self-advocacy

Allow about 10 minutes

Watch this video to learn more about how self-advocacy started and what it means to people with learning disabilities, then answer the questions below.

Video content is not available in this format.

#### Video 4



1. How did UPIAS help sow the seed for self-advocacy?

*Provide your answer...*

#### Answer

UPIAS said that people were not disabled by their bodies or minds, but by how they were treated by society. They said it was time for disabled people to start talking about what they wanted and needed, and that society needed to listen.

2. Why was Gary Bourlet so excited about self-advocacy when he visited the People First conference in Washington in 1984?

*Provide your answer...*

#### Answer

Gary talked about his surprise at how confident people were, how they were speaking out for themselves. He wanted to be like that and was inspired to set up a People First Group in London when he got back.

3. What were some of the early challenges for self-advocacy?

*Provide your answer...*

#### Answer

There seemed to be some concern – even from parents – about people speaking up for themselves. Some people suggested that Gary and John's group was somehow 'special' or 'unusual' and other people would not be able to do what they were doing.

It took a while for self-advocacy to get off the ground in the UK. But those early sceptics were eventually proved wrong. By the 1990s self-advocacy groups were set up all over the country, in all different types of places, by a range of different people. The numbers and power of self-advocacy groups has ebbed and flowed over the years, often due to policy and funding issues and in recent years many self-advocacy groups in the UK have seen their funding cut.

## 2.1 The impact of self-advocacy

Self-advocacy is about people with learning disabilities working together to make change. This could be about personal change, or political change. The main point about self-advocacy is that it recognises that people with learning disabilities are the experts in their own lives.

Watch this film of Kelly Edwards, a self-advocacy support worker at Northamptonshire People First self-advocacy group, talking about the importance of 'peer support'.

Video content is not available in this format.

## Video 5



Now complete Activity 4.

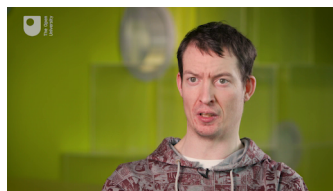
## Activity 4 The power of self-advocacy

Allow about 10 minutes

First watch this film about Shaun Picken talking about his involvement in self-advocacy group My Life My Choice.

Video content is not available in this format.

### Video 6



Now click the link below to answer the poll on what you consider the most important reason for self-advocacy.

[Link: Self-advocacy](#)

Once you have submitted your choice you can then see how others have voted.

According to Shaun, funding is also a big problem with many self-advocacy groups being forced to close. This is very concerning, especially considering how important self-advocacy groups can be for people with learning disabilities.

It is not just people with learning disabilities who are speaking up for themselves and others though. Family members also have a long history of advocating. You will explore this more in the next section.

## 3 Family advocacy

While many people with learning disabilities can speak for themselves, for others, this may be a very challenging – if not impossible – task. In these instances, parents and other family members often advocate on behalf of their relatives who cannot speak for themselves.

Listen to this short video of Phil, who you first met in Session 1, talking about how his parents were in the ‘vanguard’ of the social policy changes that have happened since the mid-twentieth century:

Video content is not available in this format.

### Video 7



Family advocacy really took off in the post-war period. Parents who were unhappy that their children were being denied access to education started actively campaigning and networking with each other.

The organisation which later became Mencap (England and Wales) was founded in the 1940s and Enable (Scotland) was founded in 1954. The energy and passion of collective parent advocacy has revived since austerity measures began to impact on social care after 2008. But family advocates often report how hard they’ve had to fight to ensure their relatives get the support and care they need. For many, it’s something that they think about 24/7 and the strain often affects their own health and wellbeing (Walmsley et al., 2017).

### 3.1 Advocating for life

Many people with learning disabilities rely on their families to advocate on their behalf. This is a role that often lasts a lifetime, and the physical, mental, emotional and financial impact on family carers can be significant.

#### Activity 5 Parent perspectives

Allow about 10 minutes

Watch this video from *Learn with Us* where you will hear short accounts from three parents: Margaret, Jean and Norman. You will also hear briefly from Maureen, a practitioner. As you listen, make a note of any comments made by the parents that really stand out for you. Also make a note of how you think the parents’ lives have been affected by their caring responsibilities. Write your thoughts in the box below.

Video content is not available in this format.



## Video 8



*Provide your answer...*

### Discussion

Comments that you might have noted down include: 'horrific'; 'I feel I am his voice'; 'lots of tears and anguish'; 'parents have to become tough'; 'damages their health'.

You may have identified that the parents experience: constant worry (including when the children leaves home); anxiety about being seen as overprotective; trying to strike a hard balance between advocating but being viewed as 'interfering'; having their own life chances affected.

Family advocates could be helped by being listened to and developing trusted relationships with services and practitioners. Jean, one of the family carers in the *Learn with Us* film, said:



The biggest thing for family carers is to realise that other people can actually do things with your son and daughter far better than you. Took us a long long time to recognise and appreciate that. You think you're the best in the world and no one else in the world can do it but you. And you can't.

5

**Figure 1** Developing trust in services can be difficult for family carers



Self-advocates and family advocates often fight for very specific improvements to an individual's life. But they also come together collectively to press for wider social change. In the next section, you will learn more about the changing policy landscape in learning disability in recent years, and the impact this has had on people's lives.

## 4 Changing the system

The rights of people with learning disabilities were emphasised strongly in the 2001 *Valuing People* White Paper. This was the first policy document in England and Wales to focus on learning disability for 30 years. In Scotland, *The Same as You* policy was published in 2000.

### Activity 6 *Valuing People*

Allow about 10 minutes

Watch this short video about the *Valuing People* White Paper and then think about what you consider to be its most important aspects by answering the poll at the link below.

Video content is not available in this format.

#### Video 9



[Link: The value of \*Valuing People\*](#)

Once you have submitted your choice you can then see how others have voted.

*Valuing People* is recognised as a landmark piece of policy in learning disability. But it is also acknowledged that *Valuing People* did not create the widespread change that people hoped it would. Some of the changes it advocated – such as closing day centres – have since been criticised for reducing people's opportunities to socialise, and putting more pressure on families.

## 4.1 The impact of austerity

Just seven years after *Valuing People* was published, the financial crash of 2008 happened. The squeeze on funding for public services that followed made it very difficult for even the most progressive local authorities and services to support people with learning disabilities in the way they wanted.

### Activity 7 Service cuts

Allow about 10 minutes

1. Watch this next video of Professor De Shutter (UN Committee on Economic, Social and Cultural Rights) speaking about the impact of austerity on the lives of people with learning disabilities. Then answer the question that follows.

Video content is not available in this format.

#### Video 10



What were some of the terms used by Professor De Shutter (UN Committee on Economic, Social and Cultural Rights) to describe the situation in the UK in 2016?

Provide your answer...

#### Answer

You may have been surprised, or even shocked to hear some of the words used by Professor De Shutter. He talked about the 'flagrant and systematic violation' of people's rights in Britain, which was 'very unique' and 'unprecedented'. He said it was an 'extreme situation'.

2. Now watch the next video about the situation of people with learning disabilities in residential care. Then complete the drag and drop activity that follows.

Video content is not available in this format.

**Video 11**



Match each situation with the United Nations Convention on Rights of Persons with Disabilities (UNCRPD) rights that might be compromised when a person lives in residential care.

**Article 19:** right to live where and with who you want

**Article 22:** right to privacy

**Article 21:** right to say what you want and access information

**Article 23:** right to a home, family, marriage and relationships

**Article 27:** right to work

Match each of the items above to an item below.

The person can be moved out of their house by a care provider or local authority because someone else needs it for cost reasons

The person has no say who comes in and out of the front door

The person has no say over who supports them

The person has no say over whether someone can stay over

The benefits system in residential care stops people from working

Cuts to funding and changes to the benefits system have been pretty devastating for some people with learning disabilities in recent years. As this activity has shown, people's lives continue to be restricted by systems and policies that they have no control over. In the next section, you will consider the impact of attitudes.

## 4.2 Changing attitudes

Are laws, policies, statements of rights and even resources enough to ensure people with learning disabilities live their lives as equal citizens? Or for people to truly feel like they belong, do wider attitudes towards learning disabilities need to change? Complete Activity 8 now which asks you to consider what factors could help to change attitudes.

### Activity 8 How people are valued

Allow about 5 minutes

First watch this video of Jan Walmsley, co-author of this course and expert in the social history of learning disability, talking about attitudes towards people with learning disabilities.

Video content is not available in this format.

#### Video 12



Now click the link below to answer the poll on what you consider the most significant factor needed to encourage people to change their attitudes and value those with learning disabilities more.

[Link: Changing attitudes](#)

Once you have submitted your choice you can then see how others have voted.

Changing society's attitudes towards people with learning disabilities is one of the greatest challenges in helping people to feel like they belong. Prejudice can be very entrenched and difficult to tackle. It is important that more is done to shine a light on the challenges that people with learning disabilities face in their day-to-day life.

There is also a need to see and hear more examples of the positive contributions that people with learning disabilities make, and how they are valued by friends, family, and the wider community.

In the final section of this session, you will explore the important role of the workforce in helping people to feel like they belong.

## 5 Working with people with learning disabilities

In this course, you've heard a lot about the experiences of people with learning disabilities and their families.

Now you will turn to look in more depth at what it's like to work with people with learning disabilities, and why people want to do it.

### Box 1 The social care workforce in England in 2018

Most people who support people with learning disabilities are in the social care workforce, one characterised by low wages, poor working conditions and high staff turnover. Here are some key facts about the social care workforce in 2018:

- Accounts for 1.6 million jobs.
- A quarter of the workforce (25%) are on a zero-hours contract (335,000 jobs).
- The staff turnover rate was 30.7%, equivalent to around 390,000 leavers in the previous year.
- Many of these leavers move to other roles within the sector as 67% of recruitment is from within adult social care.
- Workers had, on average, 8.2 years of experience in the sector.
- The vacancy rate was 8.0%, equivalent to around 110,000 vacancies at any given time. The majority of these vacancies (76,000) were care workers.
- A fifth of all workers (320,000 jobs) were aged over 55 years old.
- The majority (82%) of the adult social care workforce were British, 8% (104,000 jobs) had an EU nationality and 10% (130,000 jobs) were of a non-EU nationality.

(Source: Skills for Care, 2018)

### Activity 9 The view of a support worker

Allow about 10 minutes

Kelly Edwards has worked with people with learning disabilities for over 30 years. She is employed as a support worker for a self-advocacy organisation, but is also a carer for people with learning disabilities who need one-to-one support.

Watch this film of Kelly Edwards talking about her job.

Video content is not available in this format.

**Video 13**





Complete the table below based on Kelly's views:

**Table 1 Supporting people with learning disabilities**

The qualities and skills Kelly thinks are needed to do the job	Why Kelly likes the job	What Kelly has found difficult about the job
<i>Provide your answer...</i>	<i>Provide your answer...</i>	<i>Provide your answer...</i>

#### Answer

Here are some of the things you might have noted down:

**Table 1 Supporting people with learning disabilities (completed)**

The qualities and skills Kelly thinks are needed to do the job	Why Kelly likes the job	What Kelly has found difficult about the job
Being caring	Seeing people achieve	Cuts to funding
Being patient	Making a difference to people's lives	Seeing people lose their support hours
Being thick-skinned	Seeing people happy	Seeing people struggle with changes to the benefits system
Having a sense of humour		

You may have noticed that Kelly also said that people with learning disabilities have taught her most of what she needs to know to do the job well. Kelly enjoys her job and takes great pride in it. The challenges of the job that she describes are all related to wider social and political issues – cuts to funding and changes in the benefits system. What Kelly continues to like about her job is having the opportunity to work alongside people with learning disabilities, and supporting them to live the lives they want.

Good support is vital for people with learning disabilities. It's crucial that great care is taken to recruit the right people to the job, to train them properly, and to give them good working conditions. This is a key challenge for the future.



## 6 This session's quiz

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It's now time to complete the Session 8 badged quiz. It is similar to the previous quizzes but this time, instead of answering 5 questions there will be 15, covering Sessions 5–8.

[Session 8 compulsory badge quiz](#)

Remember that the quiz counts towards your badge. If you're not successful the first time, you can attempt the quiz again in 24 hours.

Open the quiz in a new tab or window by holding down Ctrl (or Cmd on a Mac) when you click the link. Come back here when you are done.

## 7 Summary of Session 8

In this session you have learned that people with learning disabilities have the same rights as everyone else, but that these rights are not always upheld. The system needs to change, funding needs to improve, attitudes need to shift, and people with learning disabilities and their families must continue to be empowered to speak out and ask difficult questions.

In this session you explored:

- why it has proved so hard for people with learning disabilities to have their rights upheld
- the role of self-advocacy and family advocacy in helping people to understand their rights and get their voices heard
- the role of the workforce in helping people to uphold their rights.

A whole range of people with learning disabilities, families, support workers, academics, activists, professionals, commissioners and policy-makers are working hard to make things better, but this course has shown there is still a long way to go if people are able to feel like they truly belong in society.

### Activity 10 Make a pledge

In 2018, the BELONG Manifesto was launched by Access all Areas, Beyond Words and The Open University. Read through the BELONG Manifesto, which is designed to get people thinking about what is needed to help people feel like they belong. You should open the manifesto in a new tab or window by holding down Ctrl (or Cmd on a Mac) when you click the link.

[Link: BELONG Manifesto](#)

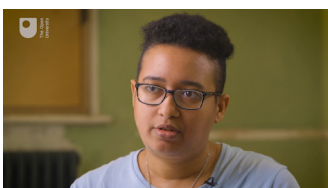
Is there anything that you think you can do to help make a difference to the lives of people with learning disabilities? Make your pledge here and then revisit it in a few days, weeks and months. You can connect with other people who are interested in the Manifesto using the hashtag #LDBelong.

*Provide your answer...*

The final word of this course goes to Charlene.

Video content is not available in this format.

### Video 14





## Want to know more?

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- If you want to know more about people's rights over the past century, read *The Road to Citizenship*:  
<https://inclusivearchive.org/story/6/the-road-to-citizenship-by-jan-walmsley/>
- Watch a Balance of Rights film in full: <https://vimeo.com/262190581>
- EasyRead Version of the UN Convention Rights of Disabled Persons:  
[https://www.equalityhumanrights.com/sites/default/files/uncrpd\\_guide\\_easyread.pdf](https://www.equalityhumanrights.com/sites/default/files/uncrpd_guide_easyread.pdf)
- Purple Patch History of Learning Disability Timeline: <https://vimeo.com/130333304>
- Article about family advocacy:  
[http://oro.open.ac.uk/49494/3/Changing face of parent advocacy pre proof version FINAL.pdf](http://oro.open.ac.uk/49494/3/Changing_face_of_parent_advocacy_pre_proof_version_FINAL.pdf)
- The Rightful Lives website: <http://rightfullives.net/>
- The state of the adult social care sector and workforce in England 2018:  
<https://www.skillsforcare.org.uk/NMDS-SC-intelligence/Workforce-intelligence/documents/State-of-the-adult-social-care-sector/The-state-of-infographic-2018.pdf>

## Where next?

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If you've enjoyed this course you can find more free resources and courses on [OpenLearn](#).

New to University study? You may be interested in our courses on [Health and Wellbeing](#).

Making the decision to study can be a big step and The Open University has over 40 years of experience supporting its students through their chosen learning paths. You can find out more about studying with us by [visiting our online prospectus](#).

## Tell us what you think

Now you've come to the end of the course, we would appreciate a few minutes of your time to complete this short [end-of-course survey](#) (you may have already completed this survey at the end of Session 4). We'd like to find out a bit about your experience of studying the course and what you plan to do next. We will use this information to provide better online experiences for all our learners and to share our findings with others. Participation will be completely confidential and we will not pass on your details to others.

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## Tables

Table 1: Learning disability statistics in England: Public Health England Public Health England (2016) Learning Disabilities Observatory: People with Learning Disabilities in England 2015 London, Public Health England.

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