NHS
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Equal Health

Skilled Learning Resource

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Contents

Introduction

Module 1 Understanding learning disability and health equality

Contents

Module 2 Person- and family-centred approaches to promoting equal health

Module 3 Promoting health and well-being for people with learning disabilities

Contents

Module 4 Supporting people with particular health needs

Contents

Module 5 Human rights, learning disabilities and equal health

Equal Health

Skilled Learning Resource

Introduction

Welcome!

Welcome to the **Equal Health – Skilled Learning Resource.** The resource has been developed for all staff who support people with learning disabilities, their families and carers and is designed to help improve your knowledge and skills in ensuring the people you work with have equal health, using a human rights-based approach.

Who is this learning resource for?

The resource is for people who work directly with people with learning disabilities, and for those who have substantial contact with people with learning disabilities, their families and carers.

The learning in this resource will help support you to develop the knowledge and skills set out at the Skilled Practice Level in Health Equalities for people with learning disabilities of **Equal Health: an educational framework on health equalities for people with learning disabilities for all practitioners working with people with learning disabilities: a human rights-based approach.**

Background

People with learning disabilities may experience health inequalities for a number of reasons that we will explore throughout the resource. We will also look at how you can help address them.

Health inequalities can have a profound impact on the families, friends and wider support networks of people with learning disabilities. They too need our support to help them enjoy the best quality of life. Wider communities also have a role in supporting people with learning disabilities to access services that affect their health and well-being.

Scotland has been developing and implementing strategies to improve the health of people with learning disabilities since 2011, including the **Keys to Life** policy and its implementation plan. **Equal Health: an educational framework on health equalities for people with learning disabilities for all practitioners working with people with learning disabilities: a human rights-based approach** was developed to support implementation of the strategies.

The **Equal Health** framework describes levels of knowledge and skills required by **ALL** staff who have a role in supporting people with learning disabilities:

- Informed Practice Level in Health Equalities
- Skilled Practice Level in Health Equalities
- Enhanced Practice Level in Health Equalities
- Specialist Practice Level in Health Equalities.

This resource is designed to help you achieve the knowledge and skills set out at the **Skilled Practice Level**.

Before you start using, facilitating or delivering training with the resource, you should ensure you have gained the knowledge and skills set out at the Informed Practice Level. To enable this, we have produced the **Equal Health Informed** DVD. If you have already seen the DVD or used it in a learning session, you may want to refresh your memory as it identifies a starting point for this resource. If you have not seen it, you should watch it now.

Introduction

How is the resource structured?

The resource has five modules. It is important that you work through Module 1 first to make sure you have a strong knowledge base on learning disabilities. The learning outcomes for the modules and the learning activities have been written to reflect Level 7 of the Scottish Credit and Qualifications Framework (SCQF). The modules include suggestions for further learning for people who choose to explore issues in greater depth.

The modules are:

Module 1
Understanding learning disability and health equality

Module 2
Person- and family-centred approaches to promoting equal health

Module 3
Promoting health and well-being for people with learning disabilities

Module 4
Supporting people with particular health needs

Module 5
Human rights, learning disabilities and equal health

We use different types of learning activities throughout the resource. These will help you reflect on how best you can support people with learning disabilities, their families and carers, and put your learning into practice. The activities will play a key part in helping you develop the knowledge, skills and attitudes that are central to your role. The focus is on practical applications of the learning, reflective practice and putting learning into action.

Introduction

How should this resource be used?

We want you to use this resource in the way that best suits you, your team and your organisation.

What is the best approach to getting started?

We would encourage individual learners, teams and organisations to consider the knowledge and skills set out at the Skilled Practice Level of the **Equal Health** framework as a first step in planning. You can find the framework on the NHS Education for Scotland (NES) website.

This will assist:

- **organisations** to think about priorities and plans for workforce development, considering the current levels of knowledge and skills in the organisation, and aspirations for future developments
- **teams** to consider the current knowledge and skills held as a team, including existing strengths and priority areas for development
- **individual learners** to consider their existing strengths and learning needs to help them prioritise how they will work through the modules.

What are the best approaches to learning and teaching?

The resource can be used for individual learning, learning as a group or team, in a facilitated teaching and learning event, or in a mixture of all of these approaches.

The resource enables learners to:

- focus on one module at a time, using the variety of activities we have provided (but we do recommend that Module 1 be completed first)
- prioritise particular modules/areas of learning based on the analysis of learning needs undertaken at organisational, team or individual learner level
- discuss their thoughts and responses with colleagues in, for example, team meetings, workshops or study sessions
- study individually, reflecting on the activities in their own time
- work with a facilitator in dedicated teaching/learning sessions
- confirm progress against the key learning points at the end of each module
- check out links to other resources to enhance development
- involve colleagues from a range of disciplines or agencies in joint learning
- use the resource as part of supervision
- build a portfolio of evidence that may support learners to confirm they have met requirements for their continuing development or gain qualifications.

Whatever approach is favoured, we recommend that learners are provided with opportunities for reflective discussion with their supervisors, and group discussions with peers and teams. This will help to put learners' individual experiences into a broader context and enhance their learning.

Introduction

How long will it take to complete the modules/resource?

This will depend on your starting point and your prior knowledge and skills. We would suggest, however, that each module will take about **four hours** to complete as an individual learner. Facilitated learning/teaching sessions **for each module** should be at least two hours in duration, with self-study prior to or after the session.

How does the learning in this resource contribute to wider development opportunities?

The varied learning activities, reflective exercises and action points contained in this resource:

- invite reflection on the learning gained, and how learning can be integrated into practice
- help you to make connections with relevant standards, continuing professional development (CPD) opportunities and qualifications.

Social services workers

Social services workers undertaking and recording the learning activities may provide evidence for inclusion in a portfolio of evidence for Scottish Vocational Qualification (SVQs) Social Services and Healthcare. This includes people who may be working towards:

- achieving awards for registration with the Scottish Social Services Council (SSSC)
- furthering their CPD.

In all cases, the extent to which learners can apply evidence from their learning journeys throughout the resource will depend on the quality and depth brought to their reflective writing.

To support social services workers to gather and express this evidence more fully, reflective account exercises are included at the end of each module, designed to help meet the learning outcomes of each module at Level 7 of the SCQF. The reflective exercises will also be useful for wider social services staff in recording CPD and in meeting post-registration training and learning requirements.

SVQ assessors and others who are supporting and assessing workers' learning may find the reflective account exercises useful in planning, teaching and assessing.

Nurses and midwives

The Nursing and Midwifery Council (NMC) introduced a revalidation process in 2015 setting out requirements that include registrants submitting evidence of CPD and the submission and verification of reflective practice accounts.

NMC registrants should be able to use the learning enabled via this resource to:

- verify they have undertaken the CPD required
- apply learning to reflect on, and improve, their practice.

Introduction

Getting started with the learning

Next, we'll introduce you to the people with learning disabilities who feature in this resource. These are fictitious characters, although their stories and experiences reflect those of real people with learning disabilities.

All of them live lives rich in experience, have loved and been loved and have pursued their individual interests. As people who care for and support others, you will already know that your commitment to the people you work with makes a difference to them achieving equal health.

So let us introduce you to:

Sheila and Nan

Sheila is 50 and lives at home with her mother Nan, who is 75 and widowed. Sheila works in a café run by an organisation that supports people with learning disabilities. She is particularly fond of swimming and dancing, attends local clubs for both activities and has a wide range of friends through work and leisure activities.

Nan is 75. She was a Sunday school-teacher and remains an active member of her local church. She has a particular interest in art and occasionally paints watercolours as a hobby. Nan's sister, Claire, lives in London, but they remain in regular contact by phone. Claire tries to visit as often as possible and has always had a close relationship with Sheila.

Sheila has been identified as having a moderate learning disability. Nan's contribution to supporting Sheila is vital. It is she who ensures that Sheila carries out daily tasks such as managing her hygiene, dressing appropriately and preparing and eating food safely. Nan is keen to support Sheila to maintain links with the local community.

Fred, Joan and Stephen

Fred, who is 19, lives at home with his mother Joan and his brother Stephen. They live in a small house on a council housing estate. Fred left school at 17 and went to college until he was 18. He is currently unemployed. Joan relies on benefits for her income and Stephen, aged 26, is also unemployed. While Fred does not have any friends of his own and can be quite anxious in unfamiliar social situations, he likes to go to the pub with his brother and his friends.

His parents have had a fairly acrimonious divorce. Fred still sees his dad once a week, when they usually go to the rugby or football together and for a few drinks afterwards.

Fred has a mild learning disability and has been diagnosed as autistic. He has DiGeorge syndrome, which has led to him having heart problems, for which he needs to take medication, and impaired hearing.

Introduction

Emily

Emily is 30 years old. She lives in a care-home setting with 24-hour support. Her family visit her once a year on her birthday.

Complications at Emily's birth meant she was starved of oxygen for some time. She has cerebral palsy and quadriplegia. She is also blind and is totally dependent on staff to meet all her needs.

Emily does not have interaction with people apart from the staff who support her. She enjoys listening to music and reacts to things that make noises. Emily communicates using the words 'yes' and 'no' but has been assessed by staff as not being able to engage with any conversations.

Emily spends most of her time alone in her room. She has one hour of one-to-one activities and a short session with staff from the Royal National Institute of Blind People once a week. She has not been given a chance to socialise and seems to be very isolated. Emily has all her decisions made for her by staff in the unit.

Molly

Molly is a 22-year-old woman who works part-time in a café and lives a fairly independent life. She lives in her own flat and likes to go out with her friends.

Molly had difficulties in her early life and spent time in residential child care and a series of foster homes. She was regularly bullied at school.

Over her life, she has had a lot of contact with various health and social services professionals and has been identified as having a mild learning disability.

Molly has had a number of relationships and is sexually active, but does not use regular contraception. Two years ago, she had a child who was removed at birth by a court order. Molly recently met a man and he has moved in with her.

Donald

Donald is 25 and lives with his family. He works in a local supermarket three days a week stacking shelves and helping out with the trolleys. He enjoys his work and gets on well with the other staff. He is very close to his father, who is retired, and they spend a lot of time together during the week doing various activities they both enjoy. He also has a network of friends and meets them at a 'social club' organised by a local voluntary organisation twice a week.

Donald has Down syndrome and is seen to have a moderate learning disability. He also has a congenital heart defect associated with his condition. He sometimes has some difficulty in making choices and expressing himself, which he can find distressing.

Bobby

Bobby lives in supported accommodation with two other men. Until recently, he attended a day placement. He enjoys music, dancing and watching football.

Bobby sometimes displays behaviours perceived as challenging for the staff team: this is one of the reasons he is not attending the day placement at the moment and is now spending most of his time in his home.

Staff supporting Bobby have noticed that some of his behaviours, which include self-injury, aggression and destruction of property, are increasing. Bobby does not like noise or lots of people around him. He cannot communicate verbally and has no augmentative communication system (a system used to supplement or replace speech using, for example, symbols instead of words) in place.

We use the stories of these people with learning disabilities, their families and carers throughout this resource to support application of learning. We want you to consider how the quality of their experience in achieving equal health can be improved through use of your knowledge and skill. All of us continue to learn and develop and the value of skilled practice to people with learning disabilities is immeasurable. You will benefit from this learning and consequently will be able to support people with learning disabilities, their families and carers to achieve equal health.

Module 1

Understanding learning disability and health equality

Module 1

Understanding learning disability and health equality

Learning outcomes

By the end of this module you will be able to:

1. understand the concept of learning disability and how it may affect people's lives
2. begin to appreciate that every person with a learning disability is a unique person with unique strengths, abilities and assets
3. identify the common health issues people with learning disabilities may have
4. begin to reflect on some of the issues that people with learning disabilities may face when accessing health services and how they may experience healthcare
5. understand the reasons why people with learning disabilities may experience health inequalities.

Introduction

We look in this module at definitions of learning disability and explore how having a learning disability may affect people's lives and health. Defining and diagnosing learning disability is complex, and we emphasise throughout the module that everyone who has this label is also a unique person with unique strengths, abilities and assets.

We consider some of the issues people with learning disabilities may face when accessing health services and how they may experience healthcare, positively and negatively. We also explore why people with learning disabilities may be at particular risk of health inequalities.

What is learning disability?

Definitions, language and labelling

We assume that if you are using this resource, you will have some experience of working with people with learning disabilities and an understanding of what learning disability is.

Learning disability is the term the Scottish Government uses in its policy and practice documents and is the term we will use in this resource.

People defined as having a learning disability have a lifelong condition that started before adulthood, which affected their development and which means they may need help to:

- understand information
- learn new skills
- live a fulfilling, healthy life.

People with a learning disability may find it harder to understand, learn and remember new things, meaning they may need support with, for example, communication, being aware of risks or managing everyday tasks, maintaining meaningful relationships and living a fulfilling life.

This is only part of the description, however. There is more to a person than just being labelled with a 'learning disability'. The label can get in the way of seeing people as being the same as everyone else, with the same rights and potential to grow and develop. With the right support, people can be enabled to learn new skills, build and sustain relationships, live fulfilling lives and contribute as active citizens in society.

Let's take a moment to reflect on the issue of learning disability and 'labelling'.

In the Introduction to the resource, you met Sheila and Nan.

Module 1

Understanding learning disability and health equality

Sheila and Nan

Sheila is 50 and lives at home with her mother Nan, who is 75 and widowed. Sheila works in a café run by an organisation that supports people with learning disabilities. She is particularly fond of swimming and dancing, attends local clubs for both activities and has a wide range of friends through work and leisure activities.

Nan is 75. She was a Sunday school-teacher and remains an active member of her local church. She has a particular interest in art and occasionally paints watercolours as a hobby. Nan's sister, Claire, lives in London, but they remain in regular contact by phone. Claire tries to visit as often as possible and has always had a close relationship with Sheila.

Sheila has been identified as having a moderate learning disability. Nan's contribution to supporting Sheila is vital. It is she who ensures that Sheila carries out daily tasks such as managing her hygiene, dressing appropriately and preparing and eating food safely. Nan is keen to support Sheila to maintain links with the local community.

Often the language used in a society reveals stigma and discrimination. This can be the case in describing people with a learning disability, where we know that derogatory and negative terms can be used.

Here is what some health and social services staff had to say about Sheila.

- *Sheila is an ageing woman with a learning disability who is almost totally dependent on her mother.*
- *Sheila has a moderate learning disability but functions reasonably well with her mother's support.*
- *Sheila works in a café. She has a wide range of friends and an active social life. She lives with her mother and has a learning disability.*

Reflection

If you were Sheila, which of the descriptions would you prefer was used about you. Why?

Think about the language used in your service or your own practice – do you think any positive changes could be made?

Record your answers here.

Module 1

Understanding learning disability and health equality

Understanding learning disability as a continuum

Learning disability is often described in terms of an intelligence quotient (IQ) of less than 70. But it is important to remember the term 'learning disability' covers a broad range of people, each with different strengths and capabilities, as well as support needs.

Knowing the IQ of a person you support may tell you very little about who they are and their needs, strengths and assets. Sometimes the IQ may help people and those who support them in understanding and designing their support. But we need to remember that while in the past a diagnosis of a learning disability and understanding of a person's needs were based on IQ scores, today the importance of a holistic approach is recognised. IQ testing forms only one small part of assessing someone's strengths and support needs.

The British Institute of Learning Disabilities (BILD) provides useful information about how we can understand learning disability as a continuum. The following definitions have been informed by, and adapted from, those of BILD and Promoting a More Inclusive Society (PAMIS), the organisation that supports people with profound and multiple learning disabilities.

People with a mild learning disability

People with a *mild learning disability* generally have an IQ of 50 to 70 and are usually able to hold a conversation and communicate most of their needs and wishes. They may need some support to understand abstract or complex ideas. People are often independent in caring for themselves and doing many everyday tasks and many may be in paid employment or further education. People with a mild learning disability usually have some basic reading and writing skills and quite often go undiagnosed as having a learning disability.

People with a moderate learning disability

People with a *moderate learning disability* may have an IQ of 35 to 50 and are likely to have some language skills that mean they can communicate about their day-to-day needs and wishes. Some may need more support caring for themselves, but many will be able to carry out daily tasks.

People with a severe learning disability

People with a *severe learning disability* may have an IQ of between 20 and 35. They may often use basic words and gestures to communicate their needs. Many need a high level of support with everyday activities, but may be able to look after some, if not all, of their own personal care needs. Some may have additional medical needs or may require support with mobility issues.

People with profound and multiple learning disabilities

People with *profound and multiple learning disabilities* (PMLD) are among the most disadvantaged in society. They have a profound intellectual disability, with an IQ of less than 20. Although there is no nationally or internationally agreed definition of PMLD, it is agreed that people will have a range of complex needs that include a profound learning disability and a physical disability that seriously affects their ability to undertake everyday tasks and which is likely to limit their mobility. Most are therefore life-long wheelchair users.

People with PMLD are likely to have sensory impairments, with either vision or hearing affected, and with some experiencing limitations to both. A significant number also have epilepsy. Their communication is usually nonverbal, though some have limited speech. All, however, have the capacity to communicate in a variety of ways.

Their healthcare needs are complex and may be life-threatening. Areas of particular difficulty relate to respiration, eating and drinking (dysphagia) and cerebral palsy. Some will also have behaviour perceived as challenging. Family carers routinely carry out intensive 24-hour care programmes to provide support and a good quality of life.

Learning disability is a way of categorising how people may experience difficulties in their lives: it is not an illness per se. It may be identified early in the person's life, but for others, it may take longer: some may never be recognised as having a learning disability, meaning they do not access the support they need.

Remember

When providing care and support, knowing the person as a unique individual should always come first, and the label or how his or her learning disability is categorised comes second.

We further explore the importance of person-centred approaches to supporting people with learning disabilities to achieve equal health in Module 2.

Module 1

Understanding learning disability and health equality

How many people in Scotland have a diagnosis of learning disability?

The Scottish Commission for Learning Disability (SCLD) is a charitable organisation and a key partner in supporting implementation of the **Keys to Life**, Scotland's learning disability strategy and action plan.

The SCLD publish statistics every year about the number of people with learning disabilities who are known to local authorities in Scotland.

From the SCLD August 2016 report, we know that in 2015:

- 27,218 adults in Scotland had learning disabilities: this equates to 6.1 people per 1,000 adults in the general population
- 4,617 adults were identified as being on the autism spectrum; of these, 70% were known to have learning disabilities
- most adults with learning disabilities and/or who are on the autism spectrum and are known to services are men (59.4%); women represent 40.6% of people with learning disabilities and/or who are on the autism spectrum known to local authorities.

If you want to find out more detail about the number of people with learning disabilities in the area in which you work, you should visit the SCLD website.

SCLD provide much more detail in their annual statistical reports, including national and local information about people's living arrangements, ethnic backgrounds and employment patterns.

Understanding why people may develop learning disabilities

The cause of learning disabilities for many people is never known, but it can be identified for others.

The possible causes of learning disability are often grouped into categories:

- **at conception**, including genetic or 'congenital' causes such as Down syndrome or Fragile-X syndrome
- **during pregnancy**, things that affect a baby before it is born, such as drug or alcohol use by the mother
- **during birth**, including oxygen deprivation during birth, which can lead to brain damage and cerebral palsy; it can also include injury to the baby because of complications during birth and difficulties resulting from premature birth
- **after birth**, including causes such as illnesses, injury or environmental conditions, such as meningitis, brain injury and children being deprived of attention to their basic needs and who are undernourished, neglected or physically abused
- **multiple causes,** when a person's learning disability is caused by a combination of factors that occur before, during and after birth.

(Reproduced and amended from information provided by BILD.)

Learning activity

People identified as having a learning disability may also have been identified as having a particular cause or ‘syndrome’ that has resulted in their learning disability and wider health problems – autism, Down syndrome or Fragile-X syndrome, for example.

Think about a person you are working with and supporting:

☐ find out more about what may have caused his or her learning disability

☐ get to know more about the people you are working with and consider if they may also have been identified as having a particular cause or ‘syndrome’ that has resulted in their learning disability and wider health problems.

Record your answers and reflections here.

Please anonymise your answers

Identify what future learning you should undertake to best inform how you can provide the best support for them.

Record your answers here.

Learning disability and health equality

What is health inequality?

Health inequalities are preventable and unjust differences in health status between groups, populations and individuals.

We explore in this section why people with learning disabilities are at particular risk of experiencing health problems and subsequent health inequalities.

Later modules will help you develop the knowledge and skills to promote equal health for the people you work with and support.

Learning activity

Take some time to reflect on your learning points from the **Equal Health Informed** DVD.

What issues have you identified that put people with learning disabilities at risk of health inequalities?

Record your answers here.

The risks people face in developing health problems

We know that people with learning disabilities may have particular health issues that mean they need proactive approaches to address any potential health inequalities.

Consider some of the facts below.

People with learning disabilities have higher levels of:

- **particular cancers:** for instance, they are three times more likely to develop cancer of their stomach and bowel, and people with Down syndrome have a higher risk of leukaemia
- **coronary heart disease:** approximately 50% of people with Down syndrome have congenital heart defects
- **respiratory disease:** this is the leading cause of death in people with learning disabilities
- **gastro-oesophageal reflux disease:** GORD, as it is known, has been identified as a significant contributor to sleep and behavioural problems, anaemia and oesophageal cancer
- **obesity:** this is particularly prevalent for people defined as having mild-to-moderate learning disabilities and has been increasing over the past 20 years; contributing factors include poor diet, lack of exercise and lack of social support
- **sensory impairment:** one in three people with learning disabilities has a sight problem, many of which could be correctable, and up to 90% of people with Down syndrome and 70% with cerebral palsy may have significant sight impairments; around 40% of adults with learning disabilities experience moderate-to-severe hearing loss

- **epilepsy:** this can be one of the most common and persistent health problems in people with PMLD, particularly if there is associated cerebral palsy, with over 60% affected; epilepsy is often misdiagnosed because the symptoms resemble a number of other conditions
- **wider health concerns:** problems may be found in relation to mobility, physical impairment, musculoskeletal conditions, oral health, dysphagia, diabetes, constipation, osteoporosis, endocrine disorders and accidents/injuries/falls
- **mental health issues:** it is estimated that people with a diagnosis of learning disability may experience increased mental health problems, such as depression and anxiety, and behavioural issues (including 'behaviours perceived as challenging'); people with Down syndrome have an increased risk of developing dementia.

Reflection

Reflecting on the health needs of the people you support:

- What issues should you be particularly alert to?
- What areas do you need to learn more about?

Record your answers here.

Please anonymise your answers

The increased health needs people with learning disabilities may have can lead to:

- shorter life expectancy than that of the general population
- poorer quality of life
- increased risk of exclusion
- conditions being undetected and therefore untreated.

In this section, we have explored some facts which indicate that people with learning disabilities have increased risks of physical and mental health problems, and how this can contribute to them experiencing health inequalities. We further explore the wider causes of health inequalities for people with learning disabilities in the next section.

Causes of health inequality for people with learning disabilities

We saw in the previous section how people with learning disabilities may be more prone to developing specific health problems. Now we briefly explore some wider issues that can determine people's equal health, including people's:

- childhood experiences and social circumstances
- ability to promote their own health and well-being and prevent health problems occurring
- opportunities to access the right healthcare support
- experiences and outcomes in the healthcare system.

People's childhood experiences and social circumstances

Unfortunately, we know that many people with learning disabilities may not have had the best start in life.

Learning activity

Remember Fred and his family and Molly, who we described in the Introduction?

Fred, Joan and Stephen

Fred, who is 19, lives at home with his mother Joan and his brother Stephen. They live in a small house on a council housing estate. Fred left school at 17 and went to college until he was 18. He is currently unemployed. Joan relies on benefits for her income and Stephen, aged 26, is also unemployed. While Fred does not have any friends of his own and can be quite anxious in unfamiliar social situations, he likes to go to the pub with his brother and his friends.

His parents have had a fairly acrimonious divorce. Fred still sees his dad once a week, when they usually go to the rugby or football together and for a few drinks afterwards.

Fred has a mild learning disability and has been diagnosed as autistic. He has DiGeorge syndrome, which has led to him having heart problems, for which he needs to take medication, and impaired hearing.

Molly

Molly is a 22-year-old woman who works part-time in a café and lives a fairly independent life. She lives in her own flat and likes to go out with her friends.

Molly had difficulties in her early life and spent time in residential child care and a series of foster homes. She was regularly bullied at school.

Over her life, she has had a lot of contact with various health and social services professionals and has been identified as having a mild learning disability.

Molly has had a number of relationships and is sexually active, but does not use regular contraception. Two years ago, she had a child who was removed at birth by a court order. Molly recently met a man and he has moved in with her.

What factors in Fred and Molly's lives might mean they are on a path to experiencing health inequalities?

Record your answers here.

Fred

Molly

You may have identified the following issues they might have faced:

- being born in poverty and living in rented, overcrowded housing
- they may not have been breastfed
- Fred's family might be smokers and heavy consumers of alcohol
- they may have had problems attending school, or have been bullied at school
- their parents might find supporting them difficult, live in poverty or have a chaotic lifestyle.

From you prior learning on health inequalities, you will recognise that these are issues that affect everyone's health. But when combined with other issues, they can have a marked effect on people with learning disabilities.

Reflection

To do this activity, you need to understand people's life histories.

Think about a person with learning disabilities you support and how understanding their early experiences helps you appreciate their health equalities more. What issues might they have experienced in their early years that could contribute to them:

- developing health inequalities
- promoting equal health?

Record your answers here.

Please anonymise your answers

Living environments, poverty and equal health

The environments in which we support people with learning disabilities can have an important effect on people's quality of life and physical and mental health. We therefore need to think about 'environments' more widely than just the physical environment, and also consider wider social aspects.

This includes thinking not only about where people live, but also issues such as how environments foster important health-promoting activities, like being active, having opportunities to engage with the wider community, and developing and maintaining friendships and social support networks.

It is estimated that just over a third of adults with learning disabilities live with their family carer and about 50% are the only person with learning disabilities living in the accommodation. Just under a quarter of adults with learning disabilities live with at least one other person with learning disabilities.

Learning activity

Please anonymise any answers.

Think about the environment (in the widest sense) in which the people you support live.

First, would you like to live there? Would it promote your health?

If your answer to each is ‘no’, explain your reasons.

How does the environment positively support people to have equal health?

Are there any aspects of the environment that might be having a negative impact on people’s health?

You might have identified the following positive areas:

- people’s accommodation has been designed in a way that is tailored to their particular needs and preferences
- environmental adaptations have been made and their home is designed around them
- person-centred plans are in place to ensure people are able to connect with their communities and enjoy a meaningful social life
- where people share accommodation with other people, it is because they or their families have chosen to do so and they live with people who get on with each other and with whom they like to live.

Negative aspects you might have identified include:

- the physical environment has not been adapted to address people’s individual needs
- people are living with others with whom they have not chosen to live
- people are isolated and have no opportunity to connect with others
- the environment they live in is not appropriate for their age.

The effects of poverty are also important to consider when thinking about the cause of unequal health for people with learning disabilities, their families and carers.

Consider these facts:

- poverty rates are higher for households with a disabled adult
- people defined as ‘disabled’ are less likely to be coping financially
- disabled people across the UK in all age categories are more likely than non-disabled people to have no bank account and no home contents insurance; this appears to be particularly true for people with learning disabilities.

We explore some of the issues highlighted above in later modules.

People's ability to promote their health and well-being and prevent health problems occurring

Personal health risks and behaviours

People with learning disabilities may lead lifestyles that put their health at risk, just as many of us do. The difference is that people with learning disabilities may not have access to the same information, choices and opportunities as other people to enable them to lead a healthy lifestyle.

Reflect on these facts.

Evidence across the UK suggests the following issues may contribute to health inequalities for people with learning disabilities:

- **diet:** less than 10% of adults with learning disabilities in supported accommodation eat a balanced diet, with insufficient intake of fruit and vegetables
- **exercise:** over 80% of adults with learning disabilities engage in physical activity below the minimum recommended levels and have a much lower level of physical activity than the general population (those with more severe learning disabilities and people living in more restrictive environments are at increased risk of inactivity)
- **weight:** people with learning disabilities are much more likely to be either underweight or obese than the general population – women with Down syndrome, for instance, are at increased risk of obesity; the high level of obesity among people with learning disabilities is likely to be associated with an increased risk of diabetes
- **substance use:** fewer adults with learning disabilities who use learning disability services smoke tobacco or drink alcohol compared to the general population, but rates of smoking are considerably higher among adolescents with mild learning disabilities and people with learning disabilities who do not use learning disability services; those with identified substance misuse issues are more likely to be male and to also misuse alcohol
- **sexual health:** evidence suggests that people may face particular barriers in accessing sexual health services and the informal channels through which young people learn about sex and sexuality.

Learning activity

Reflect on the needs of the people you work with in terms of the issues that may have a negative impact on their health.

What positive steps are you taking to support people to have a healthy lifestyle?

What areas for improvement have you identified?

Record your answers here.

Please anonymise your answers

Access to health screening

We know there is low uptake of routine screening activities among people with learning disabilities. This includes:

- assessment for vision or hearing impairments
- routine dental care
- cervical smear tests
- breast self-examination and mammography
- bowel cancer screening.

You may have been sent a postal appointment to attend for breast screening at a mobile unit or health centre, or received a test to do at home and post the sample, as is required for bowel screening. You will appreciate that this sort of general approach could provide significant barriers for some people with learning disabilities.

At this point, let us revisit Sheila's story.

Sheila

Shortly after her 50th birthday, Sheila received her first invitation for bowel screening. Nan supported Sheila to collect the samples required.

Luckily, Nan was able to support Sheila to collect her samples and enable her to participate in the screening, but people who do not have this kind of support might be excluded from screening.

Remember

People with learning disabilities have a right to equal access to health promotion activities and health screening programmes, and you can play an important role in ensuring they are able to access them.

We explore the important issues of accessible information and the adjustments people with learning disabilities need to ensure their right to equal health in later modules.

People's opportunities to access the right healthcare support

The Scottish Government's strategy for people with learning disabilities, **The Keys to Life**, states that people with learning disabilities want, and should be able to use, the same services as anyone else in society.

The strategy emphasises that specialist services should be available for people with learning disabilities when required, but that they should add to, and not replace, existing services.

But we know from research and day-to-day experience that people with learning disabilities often experience barriers to accessing health and care services and to getting the care and treatment they need.

Here are some examples of issues that make access difficult.

Communication and accessible information issues

As we explored in the DVD, people with learning disabilities may have limited or sometimes no verbal communication. It can be difficult for people to communicate pain, distress or symptoms. This can lead to delayed interventions and further complications.

The DVD also showed that people with learning disabilities may have difficulties:

- receiving communication messages due to visual, hearing or attention problems
- understanding or interpreting messages they are given because of their thinking problems

- working out what messages they want to convey because, for example, they find it difficult to correctly interpret their body's needs, such as hunger or thirst
- expressing their needs due to a lack of speech and/or other means of getting their message across.

The DVD sets out a number of strategies for enhancing communication, including:

- getting to know the person
- reading his or her nonverbal and verbal communication
- intensive interaction
- the use of objects of reference
- the use of health passports.

We further explore approaches like health passports (which we introduced in the DVD) that will help you support people's access to health services in later modules.

Health needs can also be overlooked by staff, or be wrongly attributed to the person's learning disability or associated conditions: for example, a person with a learning disability and cerebral palsy whose increasing falls are linked to his limited mobility rather than a potential visual or auditory impairment.

Health information materials may be presented in formats that are not accessible for people with learning disabilities, or focus on health issues that may not be of particular relevance to them.

Reflection

Recapping and building on your learning from completing the DVD, note here what you have learned from this module so far.

- Have you witnessed barriers being placed before people with learning disabilities that restricted their access to information, care or treatment?
- If so, what were they?
- What could you do to minimise these barriers in the future?

Record your answers here.

We explore and will further develop your knowledge and skills in this area in later modules.

People's experiences and outcomes when receiving healthcare

You may remember how people with learning disabilities shared some of their positive and negative experiences of and in health services in the DVD.

Primary (GP) care

We learned that:

- people may find it difficult to make an appointment
- routine appointment times may be too short
- people may need accessible information and health professionals need to adapt their communication style and strategies.

We should also note that people may need some more support to prepare to go to their GP and get more information about their rights to health checks and screening.

If people need to go into hospital

The points outlined in relation to primary care also apply when someone with a learning disability needs to go into hospital.

Going into hospital for any reason can be a frightening and stressful time for anyone, and may make us feel vulnerable. This is likely to be heightened for people with learning disabilities.

As we have discussed, people might find it more difficult to communicate their anxieties, or explain any pain or discomfort they may be in. They can have difficulty in adjusting to the hospital environment and routines and may have had poor experiences of healthcare in the past. Staff may not know or understand their particular needs.

Unfortunately, we also know that in the past, avoidable deaths from causes related to poor-quality healthcare have been higher for people with learning disabilities. These may be caused by:

- delay or difficulty in diagnosis
- problems with treatment
- other contributory factors, including a lack of reasonable adjustments (particularly at clinic appointments and investigations), GP referrals not mentioning people's learning disabilities, and limited use of hospital 'flagging' systems to identify people with learning disabilities.

Research into the safety of patients with learning disabilities in NHS settings also indicated delays and omissions in treatment and basic care, often caused by poor staff understanding of their specific needs and a failure to fully involve families and carers.

You may recall from the DVD that Margaret talked about how she was positively supported when going into hospital and how this made it a good experience for her.

If you are working with someone with a learning disability who needs to go into hospital, there are some good resources that can help you to support the person. These include the Department of Health publication **Working Together 2: easy steps to improve support for people with learning disabilities in hospital**, which can be found on the **Improving Health and Lives** website.

NHS Choices also has a website, **Going into hospital with a learning disability**, which has a range of useful resources including videos and easy-read guides that can be used to support people when they are planning to go to hospital.

Module summary

In this module, we have built a foundation of knowledge about learning disability on which the following modules will be built.

We have explored definitions of learning disability and explored how having a learning disability may affect people's lives and health, noting that everyone who has this label is also a unique person with unique strengths, abilities and assets.

We have also begun to consider some of the difficulties people with learning disabilities may face when accessing health services and how they may experience healthcare both positively and negatively. Some reasons why people with learning disabilities may be at particular risk of health inequalities have been explored.

You should now be able to:

1. understand the concept of learning disability and how it may affect people's lives
2. begin to appreciate that every person with a learning disability is a unique person with unique strengths, abilities and assets
3. identify the common health issues people with learning disabilities may have
4. begin to reflect on some of the issues that people with learning disabilities may face when accessing health services and how they may experience healthcare
5. understand the reasons why people with learning disabilities may experience health inequalities.

Reflective account

Write a reflective account taking into consideration your learning from Module 1.

Below is a suggested structure you may find helpful in writing your reflective account.

What happened?

Identify and describe a situation or incident in which you were supporting a person with learning disabilities to maintain his or her health. When recalling this situation, you may wish to consider the following:

- the nature of the person's learning disability
- the effect this has on the person's health
- the barriers to accessing healthcare the person may have been experiencing.

Describe what you did or how you responded.

So what does this mean?

How did you feel about the outcome of the support that you provided at the time?

What do you feel about that now, in light of your learning from the module?

What did you do that went well?

Do you think your actions helped to improve quality of life for the person you were working with?

What might you now do differently?

Now what will you do in the future?

How will this affect the way you work with people with learning disabilities in the future?

Would you act differently, or would you be likely to do the same?

What further learning do you need to undertake to enhance your understanding of learning disability that will help you to support people to achieve equal health? You may want to record this using the **paper into practice** activity at the end of the module.

Describe the outcome of your actions or response.

Paper into practice

From your learning in this module, make a note of:

- three new things you have learned about learning disability and health equalities
- three areas of practice you would like to learn more about as you continue through the learning resource
- three changes you could make that you feel would enhance your practice.

When you have completed your journey through this learning resource, return to your notes and check whether you have achieved the second and third points.

Make notes of your responses here.

Module 2

Person- and family-centred approaches to promoting equal health

Module 2

Person- and family-centred approaches to promoting equal health

Learning outcomes

By the end of this module you should:

1. appreciate the importance of communication in promoting people's equal health
2. understand the importance of person- and family-centred, strengths- and asset-based approaches in promoting health equality for people with learning disabilities
3. develop your practice to support people with learning disabilities to maintain their social networks and community connections and achieve good health
4. understand your role and develop your practice in promoting people's health and supporting their access to health services.

Introduction

Module 1 looked at definitions of learning disability and started to explore how having a learning disability may affect people's health equalities. It also stressed that everyone with a learning disability is a unique person with unique strengths, abilities and assets.

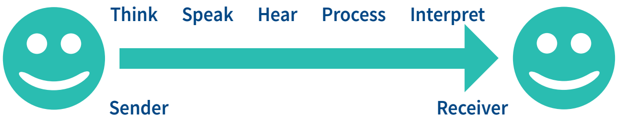
The **Equal Health Informed** DVD noted that people with learning disabilities may have particular communication needs, and this module will further develop your learning about communication. It also explores core approaches that are essential in helping to promote equal health for people with learning disabilities, including person-centred, strengths- and asset-based approaches, and the importance of community connections and social inclusion in ensuring that people with learning disabilities have equal health.

Person-centred communication with people with learning disabilities

What is communication?

Good communication is essential to providing person-centred care. Let us recap on previous learning you have probably undertaken about communication.

Communication can be defined as a two-way process in which messages and information are sent and received. Sometimes it is shown as a chain, with each link representing an element that needs to be successfully completed for the information to pass accurately from person to person – something like this:



This shows the number of processes involved in a simple exchange of information. All of them require the speaker and receiver to have a 'shared code' – a language they can each use and understand.

Other factors necessary for an exchange to be considered successful include the desire and opportunity to communicate and the exchange being pleasurable for both parties.

Learning activity

Reflect on links in the communication chain that may break down when one of the communication partners is a person with a learning disability. Make a list of the broken links you've identified below.

You may have identified that people might have difficulties with:

- receiving the message due to visual, hearing or attention problems
- understanding or interpreting the message because of cognitive impairment
- working out what information they wish to send (they find it difficult to correctly interpret their body's needs, such as hunger or thirst)
- expressing what they want or mean, due to lack of speech and/or other means of getting their message across
- having opportunities to take part in communication.

All of the above are potential areas of breakdown when communicating with someone with a learning disability, but they are based on a value judgement of the skills of only one of the communication partners – the person with a learning disability.

Remember

It is important when examining communication breakdown that we look at the communication skills of both partners involved in the process, not just those of the person that society might perceive as having the 'problem'.

Learning activity

Consider each of the accounts of communication breakdown identified on page 37 and think about how they can be described differently by identifying the actions of the communication partner who is not perceived as having communication difficulties (who could be you). We have completed the first ‘changed statement’ to let you see what we mean.

Original statement	Changed statement
Difficulty receiving the message due to visual, hearing or attention difficulties	Difficulty receiving the message because the sender has not taken into account visual or hearing difficulties or ensured that the environment is suitable to the person’s sensory/attention needs
Difficulty understanding or interpreting the message because of cognitive impairment	
Difficulty working out what information they wish to send (they find it difficult to correctly interpret their body’s needs, such as hunger or thirst)	
Difficulty expressing what they want or mean due to lack of speech and/or other means of getting their message across	
Difficulty taking part in opportunities to communicate because they appear to choose to engage in repetitive self-stimulating behaviours rather than being sociable	

You will recognise that although every link in the chain is open to breakdown, many can be mended if the communication partner facilitates the communication process effectively. Communication is a two-way process, but in this situation, responsibility is not equally shared. The communication partner – you – must carry the greater responsibility if communication is to be effective.

People with profound and multiple learning disabilities (PMLD) may face particular difficulties with communication.

Module 2

Person- and family-centred approaches to promoting equal health

Remember Emily, who we met in the introduction to the resource?

Emily

Emily is 30 years old. She lives in a care-home setting with 24-hour support. Her family visit her once a year on her birthday.

Complications at Emily's birth meant she was starved of oxygen for some time. She has cerebral palsy and quadriplegia. She is also blind and is totally dependent on staff to meet all her needs.

Emily does not have interaction with people apart from the staff who support her. She enjoys listening to music and reacts to things that make noises. Emily communicates using the words 'yes' and 'no' but has been assessed by staff as not being able to engage with any conversations.

Emily spends most of her time alone in her room. She has one hour of one-to-one activities and a short session with staff from the Royal National Institute of Blind People once a week. She has not been given a chance to socialise and seems to be very isolated. Emily has all her decisions made for her by staff in the unit.

Learning activity

What do you consider to be Emily's particular communication needs?

Record your answers here.

You will have likely identified particular issues, like Emily's limited ability to verbalise and the fact that she is blind. But it is clear also that she has very limited opportunities to communicate and grow and develop her communication skills.

If you support people who have PMLD you should further develop your learning in this area by completing the NES Learning Byte **Breaking the Barriers: communication with people with profound and multiple learning disabilities**. This is available on the NES website.

Augmentative and alternative communication

Many people with learning disabilities use augmentative and alternative communication (AAC). ACC is the term used to describe various methods of communication that can 'add-on' to speech and are used to get around problems with ordinary speech.

AAC includes simple systems such as pictures, gestures and pointing, as well as more complex techniques involving powerful computer technology. Some kinds of AAC are actually part of everyone's communication – waving goodbye or giving a 'thumbs up' instead of speaking or pointing to a picture, for example – but some people have to rely on AAC most of the time.

AAC comes in various types.

- **No-tech communication** does not involve any additional equipment and is sometimes referred to as 'unaided communication'. Examples include body language, gestures, pointing, facial expressions, vocalisations and signing.
- **Low-tech communication systems** include pen and paper to write messages or draw, alphabet and word boards, communication charts or books with pictures, photos and symbols, and particular objects used to stand for what the person needs to understand or say. This is sometimes referred to as 'aided communication' because additional equipment is required.
- **High-tech communication systems** need power from a battery or mains. Many systems speak and/or produce text. They range from simple buttons or pages that speak when touched, to very sophisticated systems. Some high-tech communication systems are based on familiar equipment such as mobile devices, tablets and laptops, while others employ equipment specially designed to support communication. This is sometimes referred to as 'aided communication' because additional equipment is required.

If you want to know more about AAC, visit the **Communication Matters** website, which has a wealth of useful information.

The most important thing is for you to really know the person you support and their particular style of communication, any aids that help them, and how you might have to adapt your communication to best support them.

In this section, we have discussed how good communication is an essential component of providing person-centred support to ensure people with learning disabilities achieve equal health. This theme will be developed throughout this and other modules.

Person- and family-centred approaches to promoting equal health for people with learning disabilities

Person-centred care – introducing the issues

The **Equal Health Framework** was designed to ensure that staff have the knowledge and skills to work in a human rights-based way that improves people's quality of life.

To help us ensure that the knowledge and skills outlined in the framework are implemented in practice, and to promote the best quality of life possible for people with learning disabilities, their families and carers, the care and support we deliver must be person- and family-centred and based on the outcomes that are important to them.

Person-centred care is based on the premise that the person is considered as central to the care and support planned, and the care and support provided.

Historically, care for people with learning disabilities has been very much goal-orientated and service-led. Person-centred care is a fundamentally different approach that aims to put the person with a learning disability at the centre of all we do. This involves exploring what is important to the person.

Person-centred care is about:

- focusing on the person's individual needs and views
- promoting the person's independence and autonomy
- providing the person with more choice and making him or her central to the decision-making process
- giving the person more control
- ensuring good communication
- building strong relationships
- providing support with compassion, dignity and respect.

To provide person-centred care, you need to:

- support the person using services or supports to describe his or her wants and needs in a way that is meaningful
- support the person using services or supports to identify and use his or her strengths to achieve goals and aspirations
- work with the person to identify the strengths and resources within his or her wider network that can play a role in supporting goal achievement.

The key role of families and carers in promoting equal health

Families are often an essential source of support in enabling people with learning disabilities to live fulfilling and meaningful lives and achieve equal health. It is crucial that we recognise and respond to their important role in this respect.

Reflect on some of the people and their families we presented to you in the Introduction.

Sheila and Nan

Sheila is 50 and lives at home with her mother Nan, who is 75 and widowed. Sheila works in a café run by an organisation that supports people with learning disabilities. She is particularly fond of swimming and dancing, attends local clubs for both activities and has a wide range of friends through work and leisure activities.

Nan is 75. She was a Sunday school-teacher and remains an active member of her local church. She has a particular interest in art and occasionally paints watercolours as a hobby. Nan's sister, Claire, lives in London, but they remain in regular contact by phone. Claire tries to visit as often as possible and has always had a close relationship with Sheila.

Sheila has been identified as having a moderate learning disability. Nan's contribution to supporting Sheila is vital. It is she who ensures that Sheila carries out daily tasks such as managing her hygiene, dressing appropriately and preparing and eating food safely. Nan is keen to support Sheila to maintain links with the local community.

Fred, Joan and Stephen

Fred, who is 19, lives at home with his mother Joan and his brother Stephen. They live in a small house on a council housing estate. Fred left school at 17 and went to college until he was 18. He is currently unemployed. Joan relies on benefits for her income and Stephen, aged 26, is also unemployed. While Fred does not have any friends of his own and can be quite anxious in unfamiliar social situations, he likes to go to the pub with his brother and his friends.

Donald

Donald is 25 and lives with his family. He works in a local supermarket three days a week stacking shelves and helping out with the trolleys. He enjoys his work and gets on well with the other members of staff. He is very close to his father, who is retired, and they spend a lot of time together during the week doing various activities they both enjoy. He also has a network of friends and meets them at a 'social club' organised by a local voluntary organisation twice a week.

Learning activity

Reflect on these three stories. Imagine that the people described did not have these family members in their lives.

What could the consequences be for them?

How could this affect their health and well-being?

Record your answers here.

Sheila

Fred

Donald

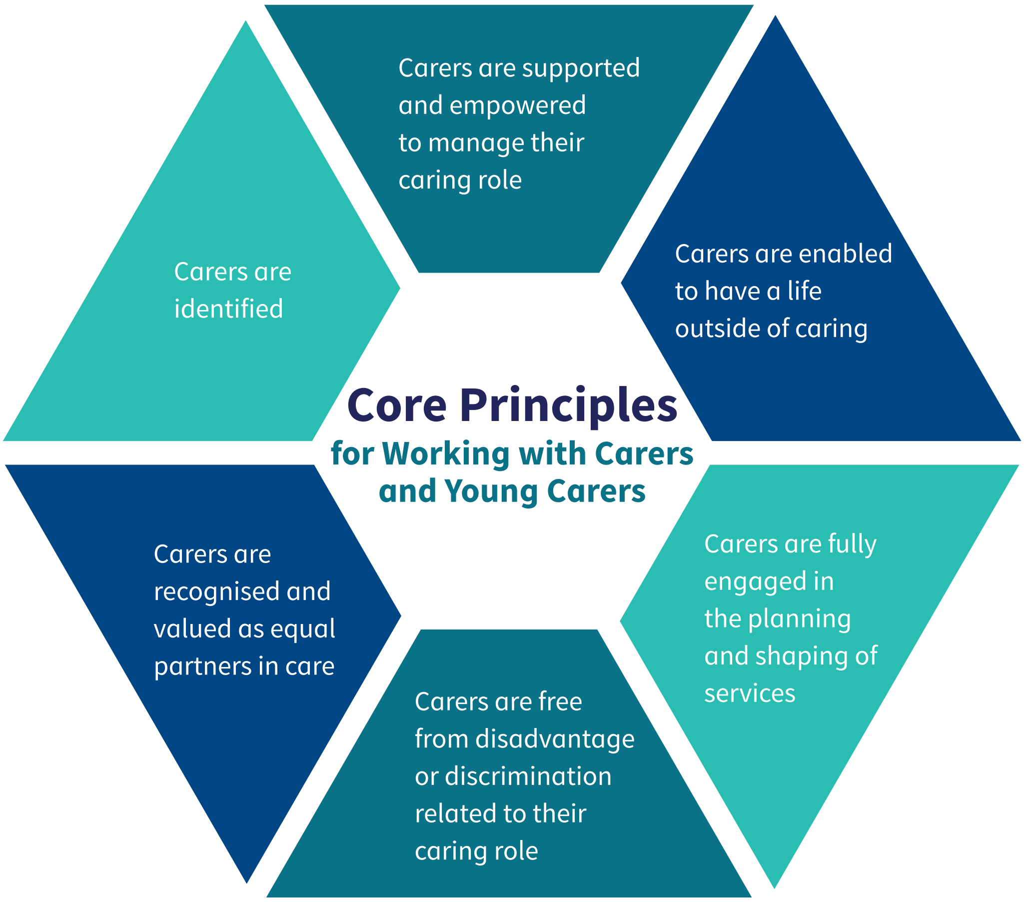
While family members and carers often play a key role in supporting people with learning disabilities and can find their relationship extremely rewarding, we also need to remember that sometimes carers may experience distress, and even depression, as a result of the pressures associated with the caring role. Carers may describe a feeling of frustration at not being involved as an equal partner in discussions about care and support, even though they are often directly affected.

You need to be skilled at recognising the needs and wishes of carers, while also ensuring the rights of the person with a learning disability remain paramount. It can be difficult to get the balance right, but if you work with the carer in a person-centred way and appreciate the potential challenges that fulfilling their role can bring, you will find it easier to build a positive relationship based on empathy and understanding. You will also find that they may have a wealth of individual information about the person with learning disability that could directly impact on their health and well-being.

To support you to work better with carers, the Scottish Social Services Council and NHS Education for Scotland have developed core principles for working with carers and young carers.

Module 2

Person- and family-centred approaches to promoting equal health



Core Principles

for Working with Carers and Young Carers

- Carers are identified
- Carers are supported and empowered to manage their caring role
- Carers are enabled to have a life outside of caring
- Carers are fully engaged in the planning and shaping of services
- Carers are free from disadvantage or discrimination related to their caring role
- Carers are recognised and valued as equal partners in care

The first step towards working better with carers is to become ‘Carer aware’. This includes understanding the definition of the word ‘carer’ and becoming more aware of the impact caring may have on a person’s physical, emotional and mental health, well-being and overall quality of life. You can learn more about working positively with families and carers by visiting the **Equal Partners in Care** (EPIC) resources on the NHS Education for Scotland **Knowledge Services** website.

Approaches to person-centred support and planning to promote equal health

Strengths- and asset-based approaches, and inclusion

We can support strengths-based approaches by focusing on what the person is able to do, rather than what he or she cannot do. This means moving away from a focus on people with ‘problems’ towards working with the person, family and carers to identify his or her strengths and abilities. We need to see the person as someone who is able to contribute within their existing role in the family, social networks and communities.

Strengths-based approaches take this a step further and recognise the value of networks, social connections and community-based support. This is referred to as an **assets-based approach**.

Supporting and enabling people with learning disabilities to contribute to and remain included in their community, rather than as someone who only receives services, can not only help them to feel valued, but can also contribute to maintaining and promoting their identity, self-esteem and, ultimately, health.

Learning activity

Look back at Sheila, Fred and Donald’s stories.

Identify the strengths and assets they have that could help promote their health and well-being.

Record your answers here.

Sheila

Fred

Donald

Module 2

Person- and family-centred approaches to promoting equal health

Some of the issues you have identified could enable them to have a socially inclusive life and participate as full citizens in society.

To promote inclusion, health and social services should support people in ways that assist them to stay or, when necessary, get connected/reconnected with their wider community. We also need a good understanding of social exclusion, how it works in society and how it affects individuals. Social exclusion involves issues such as discrimination, inequality, stigmatisation, deprivation and marginalisation. We started to explore some of these issues in the DVD and will look at them in more depth here and in later modules.

Being 'excluded' means that people do not have rights of access, opportunities or relationships. Let's consider this by revisiting the story of Bobby, who we presented in the Introduction.

Bobby

Bobby lives in supported accommodation with two other men. Until recently, he attended a day placement. He enjoys music, dancing and watching football.

Bobby sometimes displays behaviours perceived as challenging for the staff team: this is one of the reasons he is not attending the day placement at the moment and is now spending most of his time in his home.

Staff supporting Bobby have noticed that some of his behaviours, which include self-injury, aggression and destruction of property, are increasing. Bobby does not like noise or lots of people around him. He cannot communicate verbally and has no augmentative communication system (a system used to supplement or replace speech using, for example, symbols instead of words) in place.

Learning activity

How could Bobby's situation contribute to him becoming socially excluded and impact on his health and well-being?

Record your answers here.

You may have identified issues like:

- he has lost his day placement, which he previously enjoyed and which gave him opportunities to network with other people and engage in activities that were meaningful to him
- he is less physically active as a result
- he is bored being stuck in the house all day and feels angry, frustrated and fed up that he is no longer able to go to his day placement
- his frustration has led to an increase in some of the behaviours that staff perceive as challenging
- consequently, increasing restrictions are being put in place and he is on a spiral to becoming socially excluded.

We explore Bobby's situation in more detail in Module 5, demonstrating how positive support can be put in place to promote his equal health and inclusion.

Developing an asset-based focus is key to supporting people to be socially included and have equal health. To illustrate this, let's revisit Sheila and Nan's story.

Sheila and Nan

Nan had a stroke and was admitted to hospital. After being an inpatient for the past 10 days, she has now recovered sufficiently to plan her discharge.

Nan has lost some of her ability to mobilise and look after herself. She is really worried about how she will cope with supporting Sheila, although she desperately wants them to continue to live together.

When Nan was admitted to hospital, Sheila had to be placed in a local authority residential home for people with learning disabilities. It became clear during Nan's admission that Nan provides significantly more support to enable Sheila to stay at home than had previously been understood. The assessment of staff in the residential home was that given Nan's deteriorated health, Sheila's level of need indicated some form of residential or supported accommodation would be required in the future, rather than returning home.

In a situation like this, it is understandable that the focus of the staff is on deficits, problems and 'sorting out' the situation Sheila and Nan are facing. Reflect, however, on Sheila and Nan's situation in the context of a strengths- and asset-based approach.

Learning activity

What assets could be mobilised to enable Sheila to return home to live with Nan?

Record your answers here.

Remember, asset-based approaches require health and social services to pay attention to all aspects of a person's life, including personal, community and wider assets, and to assist the person to engage in things that make life rewarding.

Let's revisit Sheila and Nan's story again.

Sheila and Nan

After being an inpatient for the past 10 days, Nan has now recovered sufficiently to plan her discharge from hospital.

When Nan was admitted to hospital, Sheila had to be placed in a local authority residential home for people with learning disabilities. It became clear during Nan's admission that Nan provides significantly more support to enable Sheila to stay at home than had previously been understood. The assessment of staff in the residential home was that given Nan's deteriorated health, Sheila's level of need indicated some form of residential or supported accommodation would be required in the future, rather than returning home.

Using an assets-based approach, however, enabled staff to identify that Nan and Sheila have significant assets: their desired personal outcomes will focus on them continuing to live together and maintaining and developing the things they value in their lives.

Working in an asset-based way often calls for creative approaches to be used. Let's consider how we could use creative approaches facilitated by **self-directed support** (SDS) to enable Sheila and Nan to achieve the outcomes they have identified as important for them.

Scotland has a strategy for SDS that aims to ensure that as many people as possible can choose how their funding for social services support is spent. SDS enables people to arrange some or all of their support, instead of receiving services arranged by their local authority social work or housing department. It applies to people who would like more flexibility, choice and control over their care so they can live at home more independently.

If people choose to organise their own community care support package, they are in charge of the arrangements. This should allow them to organise their lives the way they wish. They receive a sum of money to spend on the support they need, instead of receiving council services. If they want, they can choose to organise some of their own support to complement support received from public services.

Most people who use social work services can get SDS, sometimes called **direct payments**. The term 'self-directed support' is used because it emphasises that people are in control.

People often use SDS to get support with:

- personal care, like having a bath, washing or getting dressed
- living in their own house through help with managing money, cooking and cleaning
- getting out and about to see friends, join in activities with other people, or go on a short break (respite)
- getting to work or college.

To find out more about SDS, visit the **Self-directed Support Scotland** website. Please make a point of viewing the video clips available on the website, in which people describe how SDS has worked for them.

There would be opportunities for Sheila and Nan to use SDS to, for instance, cover transport costs or employ a personal assistant to help them remain engaged in activities they value, such as:

- Sheila continuing to work in the café
- Sheila maintaining contact with her network of friends
- Sheila continuing to maintain engagement with, and participation in, the social activities she enjoys

- Sheila and Nan receiving help with personal assistance to enable them to continue to live together
- Claire (Nan's sister) being enabled to spend some time with Sheila and Nan when they both need additional support.

We have explored in this section how the use of creative, person-centred and strengths- and asset-based approaches can help people with learning disabilities to achieve equal health and stay socially included. In the next section, we discuss person- and family-centred approaches you can use to support and improve access to, and experience of, healthcare for people with learning disabilities.

Person- and family-centred approaches to support and improve access, experience and outcomes of healthcare for people with learning disabilities

In the DVD, we explored reasons why people might have difficulties accessing healthcare and have poorer experiences and outcomes than other people. You will recall we discussed issues like:

- access to health screening
- communication and accessible information issues
- people's experiences and outcomes in the healthcare system.

We also discussed this in more depth in Module 1 and began to reflect on some of the issues that people with learning disabilities may face when accessing health services, and how they may experience healthcare.

In this section, we will develop your learning further by discussing some specific person-centred approaches.

Life stories

If we know the stories from a person's life, it becomes much easier for us to see the person as an individual and support him or her. When you hear someone's life history, it becomes clear that they may have had many valued roles. This is the same for the people with learning disabilities we support.

We are often defined by our roles – wife, father, support worker, musician, and so on – and we may have several roles at any time. We need to be aware of people's roles, both past and present, and provide opportunities for them to use their skills and past experience to achieve equal health.

Finding out about the person can be achieved in many different ways. **Life-story** books with different sections and photographs, and **memory boxes** with objects that are special to the person, are frequently used. The benefit of recording someone's life story is that it can be used to communicate the person's wishes, hopes and aspirations.

The main advantages of life-story work are that it:

- enables us to support the person accessing and engaging in healthcare with what he or she wants and needs, rather than guessing
- helps us to have a better understanding of the causes of someone's behaviour, particularly if they are experiencing distress when accessing and receiving healthcare
- enables health and social services workers to form relationships with people based upon understanding and empathy to support them through their healthcare journey
- can provide the basis of health assessment and treatment planning across a range of healthcare situations and encounters by identifying what is important to the person.

Supporting a person to compile his or her life story can also be very therapeutic in developing a trusting relationship with the person. It should encourage a relationship-centred approach that recognises the relationships the person has with others.

Writing a life story should involve the person with a learning disability, the family, carers and service providers. This can then lead to them identifying a circle of support, which could include family, friends, professionals and others the person considers to be important to them. The circle of support should also include all those assets identified within the person's community.

Learning activity

Talk to one of the people you support. Try to find out about them.

Do you think he or she would benefit from a life story or memory box?

How would you go about starting this work with the person?

Record your answers here.

Compiling life stories requires sensitivity and thoughtfulness. People may have had traumatic incidents in the past that they still find difficult to confront, and it is important that you bear this in mind.

We do this by considering people's:

- personal history
- personal experience
- personality
- aspirations
- strengths
- fears
- priorities and preferences
- personal outcomes.

Personal communication and health or hospital passports

Personal communication passport

Personal communication passports were developed in Scotland in the early 1990s and are now widely used in home care, social work, education and health settings. Communication passports help make sense of formal assessment information and record important information about people in an accessible, person-centred way.

Personal communication passports aim to:

- present the person positively as an individual, not as a set of 'problems' or disabilities
- provide a place for the person's own views and preferences to be recorded and drawn to the attention of others
- reflect the person's unique character, sense of humour etc.
- describe the person's most effective means of communication and how others can best communicate with, and support, him or her
- draw together information from past and present and from different contexts to help staff and conversation partners understand the person and have successful interactions
- place equal value on the views of all who know the person well, including families and carers, as well as the views of specialist professionals.

A personal communication passport is extremely beneficial for staff working with a person with a learning disability: you can probably see similarities between these passports and the life stories you were introduced to earlier.

If you are interested in developing a personal communication passport, the **CALL Scotland** website provides excellent guidance on how to go about it, along with other useful information about communication.

Health or hospital passport

Health or hospital passports are a fairly recent development. A health or hospital passport is a booklet that a person with a learning disability can carry when attending hospitals or other providers of health and disability services. The passport is not expected to hold all the available information about the person, but contains information about how the person wants staff to communicate with and support him or her and can help improve the health of people with learning disabilities.

The passport should contain information about the person to enable staff to understand how best to support him or her in a person-centred way. It makes a connection between those who know the person least (often staff in healthcare services) and those who know him or her best (parents, carers, care coordinators, community nurses and therapists, for example). The passport is intended to help healthcare staff to offer the right information at point of contact with services and provide the necessary care and treatment during the person's stay in hospital.

A health or hospital passport can empower people by:

- providing information in a format that is easy to understand
- enabling those who support them to have better information about people's health needs and the best way to help them.

The passport supplements routine information that is usually collected and which contains the following person-centred information:

- personal information, including the names and contact details of people the person would like hospital staff to inform when they are in hospital
- communication information, giving specific detail about: any difficulties; how to communicate best with the person; how he or she will communicate with staff; and any communication aids used
- how the person might experience, express and communicate pain
- things that may cause the person distress
- the person's medication and medical history
- details about his or her capacity to consent to treatment
- eating and drinking preferences and any support needed
- any support required with continence
- any support required with mobility and positioning
- sleeping patterns and preferences
- things that will make the person's hospital stay better for them (food and drink choices, for instance)
- things that make the person happy and/or feel good, or feel unhappy: these things are important to help staff meet the person's needs and not just treat the illness and/or health problem.

It may be that the people you support already have a health or hospital passport. If this is the case, it is important for you to make use of it when the person has any interaction with health services, whether planned or during an emergency.

If the people you are supporting do not have these passports, you may wish to visit the website of your local NHS or integration joint board to see if there is a preferred approach and documentation that could help you in collating passports.

Advance planning

Advance planning enables people to be supported to think about future health and care needs, to consider their wishes and decisions and to make a plan for their care and treatment.

Some people with learning disabilities, their families and carers may be unaware of advance plans, so it is important that we provide information about them and their benefits. It is also important to remember that only decisions made by the person can be included in the advance plan.

Reflection

Take some time to consider what is important to you and key aspects that you would wish to incorporate into your advance plan.

How would you feel about sharing this information?

Record your answers here.

Did you consider any of the following?

Preferences
For example: the things you like to wear, eat and drink; music you like; hobbies or pastimes you enjoy; special interests; and what items you like to have around you.

Your spiritual and philosophical beliefs
What makes life worth living; things that have special meaning in your life.

Dislikes
Things you do not like to do, do not like others around you doing, or do not like about the environment in which you live.

What you fear most
What might take away the pleasure from your life, or cause it to lose its meaning or quality, making you fearful, anxious or distressed.

Attitudes to making decisions
How you like to make decisions – are you 'independent-minded', or do you tend to depend on the advice of others?

People who matter
Your friends and family – how and who you would like to be involved if you were not capable of making certain decisions, and the people you might not want to be involved.

Attitudes to professionals
Those who are treating you and caring for you – your relationships with doctors, nurses or others in the health and social care professions, especially the degree to which you tend to rely on their judgements.

Attitudes to illness and disability
How you might cope with illness, disability, pain and discomfort.

Attitudes to death and dying
For example, your views on giving and withholding treatment that may hasten or delay your death, where you would like to be when you die, and who you would like to have around you.

After your death
Your wishes about your funeral and who to inform about it.

Anything else
Not mentioned above, but something you identified as important to you.

Learning activity

How would you support a person with a learning disability to begin to think about what is personally important when he or she is considering future plans?

Record your answers here.

We have discussed in this section some specific person-centred approaches you can use to support people with a learning disability to improve their access to the healthcare system, to have better experiences and outcomes, and to help them achieve equal health. We will continue to develop your learning in this area in later modules.

Module 2

Person- and family-centred approaches to promoting equal health

Module summary

This module has explored core approaches that are essential in helping to promote equal health for people with learning disabilities, including person- and family-centred, strengths- and asset-based approaches. We have also explored the importance of community connections and social inclusion in ensuring people with learning disabilities have equal health.

You should now be able to:

1. appreciate the importance of communication in promoting people's equal health
2. understand the importance of person- and family-centred, strengths- and asset-based approaches in promoting health equality for people with learning disabilities
3. develop your practice to support people with learning disabilities to maintain their social networks and community connections and achieve good health
4. understand your role and develop your practice in promoting people's health and supporting their access to health services.

Reflective account

Write a reflective account taking into consideration your learning from Module 2.

Below is a suggested structure you may find helpful in writing your reflective account.

What happened?

Identify and describe a situation or incident in which you were supporting a person with learning disabilities to maintain his or her health. When recalling this situation, you may wish to consider the following.

- What particular person-centred approaches did you try?
- What particular communication skills did you use?
- How did you meaningfully involve family members and carers?

Describe what you did or how you responded.

So what does this mean?

How did you feel about the outcome of the support that you provided at the time?

What do you feel about that now, in light of your learning from the module?

What did you do that went well?

Do you think your actions helped to improve quality of life and/or access to healthcare or health equalities for the person you were working with?

What might you now do differently?

Now what will you do in the future?

How will this affect the way you work with people with learning disabilities in the future?

Would you act differently, or would you be likely to do the same?

What further learning do you need to undertake to enhance your understanding of learning disability that will help you to support people to achieve equal health? You may want to record this using the **paper into practice** activity at the end of the module.

Describe the outcome of your actions or response.

Paper into practice

From your learning in this module, make a note of:

- three new things you have learned about providing people with person-centred support to promote their health equality
- three areas of practice you would like to learn more about as you continue through the learning resource
- three changes you could make that you feel would enhance your practice.

When you have completed your journey through this learning resource, return to your notes and check whether you have achieved the second and third points.

Make notes of your responses here.

Module 3

Promoting health and well-being for people with learning disabilities

Module 3

Promoting health and well-being for people with learning disabilities

Learning outcomes

By the end of this module you should:

1. appreciate the factors that can impact on the health and well-being of people with learning disabilities
2. describe some common physical health, mental health and well-being issues that may be experienced by people with learning disabilities
3. describe how people with learning disabilities can be supported to maintain their health
4. describe how health screening/promotion can be improved for people with learning disabilities
5. further explore how access to health services can be enhanced for people with learning disabilities to improve health equalities.

Introduction

Health and well-being is important to us all, and no less for people with learning disabilities. The **Equal Health** framework identifies that people with learning disabilities should be entitled to maintain their best level of physical, mental, social and emotional well-being.

In Module 2, we explored how person-centred approaches are central to promoting the health and well-being of people with learning disabilities. In this module, we examine approaches to supporting people to keep as well as possible and maintain their physical and mental health.

In particular, we examine the macro issues around living healthy lives and maintaining good physical and mental health. The next module looks at more specific physical and mental health situations people may experience that influence their equal health and how you can further support them to achieve equal health.

Common physical health and well-being issues linked to health inequalities for people with learning disabilities

People with learning disabilities can experience a number of issues that make them more prone than the rest of the population to experiencing unequal health. In this section, we explore how these issues can impact on people's health and well-being.

Nutrition and health equality for people with learning disabilities

The prevalence of common age-related disorders among people with learning disabilities that might be linked to poor diet, such as hypertension (high blood pressure), stroke and coronary heart disease, may be similar to the prevalence in the general population.

Many of these conditions and their related ill health are avoidable. It is therefore important that you recognise the importance of providing good nutritional care for the people you support and appreciate the role good nutrition plays in promoting health and well-being.

There is considerable evidence that people with learning disabilities are more likely than those in the general population to have nutritionally-related ill health, and that this is often not recognised by health and social services staff.

Common issues people may experience relate to:

- body weight – people with learning disabilities are more prone to being overweight or underweight
- difficulties with eating and drinking, including swallowing difficulties and gastro-oesophageal reflux disorder

- diabetes, bowel disorders and oral health problems are also frequently reported among people with learning disabilities
- people with learning disabilities may be more likely to live in poverty and in more challenging circumstances, and may be socially excluded – all factors that may contribute to poorer eating patterns.

Learning activity

Think about the people you support **(please anonymise any answers)**.

How do you currently support people to have good nutritional health?

What areas have you identified for further improvement?

Record your answers here.

You may have identified important issues like:

- using the person-centred approaches we discussed in Module 2 to find out about their food preferences and eating patterns
- the need for people to be supported and have access and opportunities to eat a varied and nutritious diet
- using person-centred approaches to interpret people's wishes and choices if they have particular communication support needs around food and drink choices.

People with learning disabilities should wherever possible be encouraged by family, friends and support staff to eat a varied diet. They should eat foods from each of the four main food groups every day to ensure they get all the nutrients they need. A variety of foods and drinks should be available to everyone and people with learning disabilities should be supported to make informed choices.

It is important that you know about the milestones for people's growth and development and the importance of intervention if a person is below, or above, a healthy body weight for their height and age. It is particularly important that the person's weight is recorded monthly and that any changes are investigated. Some people will need specialist input from a dietician and you should recognise when people should be referred for this support.

Fluids and hydration and health equality for people with learning disabilities

It is important that everyone is encouraged to drink a sufficient, but not excessive, amount of fluid each day. It should not be assumed that some people with learning disabilities will necessarily drink sufficient fluid without encouragement. Most adults need at least 1.2 litres of water a day (about six glasses), but older people or those who are prone to constipation should be encouraged to have at least 1.5 litres a day (about 7–8 glasses). Excessive fluid intake (more than five litres a day) can nevertheless be very dangerous, and advice should be sought from a medical practitioner if there is concern that someone is drinking excessively.

Free, fresh, chilled tap water should always be offered with meals and regularly throughout the day and should be widely available in places where people with learning disabilities live, work or visit. The amount of soft and fizzy drinks people with learning disabilities consume might need to be considered, since these offer little nutritional benefit, may suppress people's appetite and prevent them eating more nutritious foods, and lead to dental problems.

Nutritional issues for people with profound and multiple learning disabilities (PMLD)

Do you remember Emily?

Emily

Emily is 30 years old. She lives in a care-home setting with 24-hour support. Her family visit her once a year on her birthday.

Complications at Emily's birth meant she was starved of oxygen for some time. She has cerebral palsy and quadriplegia. She is also blind and is totally dependent on staff to meet all her needs.

Emily does not have interaction with people apart from the staff who support her. She enjoys listening to music and reacts to things that make noises. Emily communicates using the words 'yes' and 'no' but has been assessed by staff as not being able to engage with any conversations.

Emily spends most of her time alone in her room. She has one hour of one-to-one activities and a short session with staff from the Royal National Institute of Blind People once a week. She has not been given a chance to socialise and seems to be very isolated. Emily has all her decisions made for her by staff in the unit.

Learning activity

Emily is dependent on others to maintain her nutrition. She has to be assisted by staff to eat and drink.

What should staff do while helping Emily with her nutrition?

Record your answers here.

You may have mentioned that it is important to support Emily in a sensitive and effective way. Helping someone who has difficulties eating and drinking on their own can be complex and stressful not only for the person, but also for the staff supporting them, so it is essential that staff are given sufficient support from colleagues when this is an issue.

All staff who support people with learning disabilities should receive first-aid training to ensure they know how to deal with choking.

You should also be alert to signs that may indicate constipation, which is often related to poor nutrition and hydration. These signs include:

- reluctance to go to the toilet
- obvious discomfort when using the toilet
- long periods spent in the toilet
- a change in eating habits
- unexplained diarrhoea
- not wanting to eat or drink
- unexplained changes in people's behaviour.

To avoid constipation, it is important that people are as mobile as possible and have sufficient fluid and fibre in their diet.

Oral health and nutrition

Oral health can affect our nutritional health, and vice versa. Like all of us, people with learning disabilities should visit the dentist twice a year. Cutting down on the total amount of sugar eaten and, in particular, the number of sugary snacks and drinks consumed throughout the day helps prevent dental decay. Good daily oral hygiene is essential, including brushing the teeth twice a day with fluoride toothpaste.

Anyone who may have difficulty in brushing their teeth independently should be helped to do so. You should be offered training on the importance of oral health and how to help someone clean their teeth. All staff who support people with learning disabilities should be alert to changes in people's behaviour: if mouth or tooth pain is thought to be a possible cause, make sure the person has an urgent check-up from a dentist.

Module 3

Promoting health and well-being for people with learning disabilities

Learning activity

How would you feel if you could not brush your own teeth?

You may like to try it with a colleague, brushing each other’s teeth. What was this like?

Record your answers here.

You probably identified that:

- it felt uncomfortable
- you weren’t sure your teeth were clean
- you had a gagging sensation.

Or many other reactions.

Exercise and physical activity to promote equal health for people with learning disabilities

Physical activity is beneficial for us all in supporting physical and mental health and enabling us to maintain and improve our health.

Physical exercise can promote and support our mobility, which in turn can:

- improve circulation and cardiovascular health
- reduce the risk of high blood pressure and heart disease
- reduce the risk of some types of cancer (such as colon and breast)
- reduce the risk of stroke and type 2 diabetes
- help people maintain a healthy weight.

It can also promote mental health and well-being by:

- promoting relaxation and a sense of calm
- helping to ensure a good night’s sleep
- reducing the likelihood of anxiety, stress and depression.

Everyone should be as active as possible, as physical activity builds muscle strength and overall fitness, encourages better mobility and balance, increases appetite and burns up calories. Activity also helps prevent constipation, coronary heart disease and osteoporosis, and has been associated with better mental health.

People with learning disabilities should be encouraged and supported to maintain any physical activities they enjoy. Local community or sports centres often provide a range of organised exercises, physical activity sessions and exercise classes, including music and dance, yoga and tai-chi, indoor bowls and swimming. Some of these activities can be modified and carried out at home if preferred.

Where people with learning disabilities also have physical disabilities that make movement difficult, they should be given help to be as active as they can be, even if this involves only very limited chair-based activities.

Learning activity

Think of three ways you could support the people with learning disabilities you work with to incorporate more physical exercise or activity into their daily routine.

Record your answers here.

Sexual health and equality for people with learning disabilities

Despite various laws, policies and guidance, it is clear that people with learning disabilities continue to face barriers and health inequalities in building and developing relationships.

People with learning disabilities, like all of us, have a right to have friends and develop relationships. We are all sexual beings, and people with learning disabilities have the right to express their sexuality. Historically, however, people's sexual needs have been ignored and their rights have gone unrecognised. Normal sexual behaviour is sometimes perceived as problematic for people with learning disabilities, with the learning disability 'label' sometimes dominating their sexual identity.

Research has highlighted a multitude of barriers or challenges that people with learning disabilities face in developing sexual relationships, including:

- general/societal attitudes
- attitudes and views of parents, staff and teachers
- barriers to the support provided in relation to contraception and complying with contraceptive methods
- limitations of sex education
- protection from abuse versus enabling relationships.

It is evident from the research that there is a significant issue for practitioners, parents and carers in negotiating the balance between protecting people with learning disabilities from abuse or exploitation and enabling relationships.

Let's revisit and build on Molly's story.

Molly

Molly is a 22-year-old woman who works part-time in a café and lives a fairly independent life. She lives in her own flat and likes to go out with her friends.

Molly had difficulties in her early life and spent time in residential child care and a series of foster homes. She was regularly bullied at school.

Over her life, she has had a lot of contact with various health and social services professionals and has been identified as having a mild learning disability.

Molly has had a number of relationships and is sexually active, but does not use regular contraception. Two years ago, she had a child who was removed at birth by a court order. Molly recently met a man and he has moved in with her.

Learning activity

Reflect on Molly's story.

What issues did it raise for you in terms of any support she may require in relation to her sexual health?

Record your answers here.

Research has identified the following factors that contribute to supporting the development of romantic and safe sexual relationships:

- promoting positive attitudes towards appropriate sexual expression
- supporting people to make choices and keep safe
- encouraging liberal, accepting and positive attitudes among staff
- facilitating or providing sex education
- ensuring privacy
- adopting positive and supportive person-centred approaches
- developing a relationship policy for local areas/services
- supporting people to use contraception effectively.

Supporting people to understand emotions, boundaries, sexual health and how to stay safe helps to develop useful life skills and a positive and healthy attitude towards sexuality and well-being.

Relationships can bring pleasure and boost self-esteem and confidence, but may also involve risks such as being hurt, pregnancy, HIV and AIDS. It can be difficult to strike a balance between protecting vulnerable people from risks and allowing them to explore and develop wider personal and social relationships.

If you want to find out more about supporting people with learning disabilities to promote equal sexual health, we recommend you access the comprehensive resource produced by NHS Lothian – **Making Choices, Keeping Safe: guidelines for those caring for people with learning disabilities around relationships and sexual health**. This can be accessed on the **NHS Lothian Learning Disability** web page.

Mental health and equal health for people with learning disabilities

Mental health and well-being is important to everyone. People with learning disabilities should have equal access to opportunities to promote their mental health and appropriate person-centred mental health support and services if they are experiencing any issues with their mental health.

Enabling equal access to mental health support for people with learning disabilities means that staff understand the mental health issues people may face, and why they might be more likely to experience problems with their mental health.

Consider the facts below.

- People with learning disabilities may have less chance of accessing opportunities to promote their mental health.
- The prevalence of mental health problems in people with learning disabilities is considerably higher than the general population – research suggests that between 27% and 41% of adults and about 40% of children with learning disabilities have a mental health problem.
- Mental health problems in people with learning disabilities were rarely recognised in the past.
- Mental health problems in people with learning disabilities are often overlooked or underestimated.
- In addition to mental health problems, people with learning disabilities often have coexisting autistic spectrum disorders, behaviours that are perceived to challenge services, and offending behaviour.

Learning activity

Reflect on Fred, Joan and Stephen's story.

Fred, Joan and Stephen

Fred, who is 19, lives at home with his mother Joan and his brother Stephen. They live in a small house on a council housing estate. Fred left school at 17 and went to college until he was 18. He is currently unemployed. Joan relies on benefits for her income and Stephen, aged 26, is also unemployed. While Fred does not have any friends of his own and can be quite anxious in unfamiliar social situations, he likes to go to the pub with his brother and his friends.

His parents have had a fairly acrimonious divorce. Fred still sees his dad once a week, when they usually go to the rugby or football together and for a few drinks afterwards.

Fred has a mild learning disability and has been diagnosed as autistic. He has DiGeorge syndrome, which has led to him having heart problems, for which he needs to take medication, and impaired hearing.

What issues (past and present) can you identify that might have a negative impact on Fred and his wider family?

Record your answers here.

Module 3

Promoting health and well-being for people with learning disabilities

Factors contributing to mental health problems

The increased prevalence of mental health problems in people with learning disabilities has been attributed to biological, psychological and social factors that may make them more likely to develop mental health issues, compromise their mental health and provide unequal opportunities to maintain good mental health. These factors can affect anyone, but people with learning disabilities are more likely to encounter them.

You may have mentioned some of the following issues when you considered Fred and his family's story in the learning activity above.

Personal and psychological factors	Social causes
Issues with self-insight and self-worth	Living in inappropriate environments
Self-image	Adverse life events
Issues with coping mechanisms	Poverty and poor housing
Bereavement and loss	Social exclusion
Issues expressing emotions	Exposure to adverse life events
History and expectation of failing	Expectations of others
Dependence on others	Family relationship issues
Physical health problems	Reduced social networks
Social anxiety	Lack of employment, education and meaningful activity

Mental health problems may arise without any cause, or be an understandable reaction to situations in people's lives. They may last a lifetime or just a few weeks. Many people who have both learning difficulties and mental health problems experience stigma, prejudice and discrimination.

Mental health problems in people with learning disabilities may also affect family, friends and carers. It can be doubly challenging to care for and support someone with learning difficulties and a mental health problem to achieve equal health. Some of these issues will be explored further in later modules.

Remember

People with learning disabilities who might be experiencing mental health issues and problems may need additional support to understand what is happening.

If you want to find out more, a range of accessible information sources explaining mental health issues and problems people with learning disabilities may experience is available on the **Royal College of Psychiatrists Learning Disability** web page.

Dementia and health equality for people with learning disabilities

Improvements in medical and social care have led to a significant increase in the life expectancy of people with learning disabilities. As with the general population, the effect of ageing on people with learning disabilities (which includes the increased risk of developing dementia) is becoming an increasingly important issue.

People with learning disabilities can be affected by dementia in very similar ways as other people, but the early stages of dementia are more likely to be missed or misinterpreted, perhaps because the person may find it hard to express his or her experiences and communication issues may make it more difficult for others to assess change.

People with Down syndrome are at particular risk, with up to 75% over the age of 60 likely to develop dementia. Prevalence of dementia in older people with other forms of learning disability is higher than in the general population, but as is the case with any suspected cognitive decline, it is important that other causes of changes are eliminated.

People with learning disabilities who are also living with dementia may not fully understand what is happening to them. Careful thought and planning by support staff should ensure that familiar language is used to explain changes. The environment should be appropriate, offering a stable, predictable and calming atmosphere. It is also important that any other physical, mental, social and emotional health needs are met: older people with learning disabilities, for instance, are more likely to be affected by arthritis and other conditions that can affect mobility, and people with Down syndrome are particularly susceptible to thyroid conditions and hearing problems. It is essential that people with learning disabilities who are living with dementia are not disadvantaged by lack of access to general healthcare.

If you want to learn more about supporting people with learning disabilities and dementia, you should access the following resources:

- **Dementia Skilled – Improving Practice Resource**, which you can find on the **NES** website
- **Jenny's Diary: a resource to support conversations about dementia with people who have a learning (intellectual) disability**, which you can find on the **University of the West of Scotland** website.

Drugs, alcohol and smoking – issues for equal health for people with learning disabilities

Levels of drug and alcohol misuse and smoking are lower in people with learning disabilities than the general population, but are nevertheless an emerging issue of concern.

Drug and alcohol misuse and smoking are less likely to be issues for people with learning disabilities where:

- they are living in supported environments
- support staff or their families are involved in people's social life
- tenancy agreements require a code of conduct from tenants
- people's money is under the supervision of workers or their families and carers.

This does not mean that substance misuse should be discounted as a health inequality issue.

People with learning disabilities living in more independent settings may have access to alcohol and cigarettes, but be restricted by lack of income. They may also have knowledge of drugs, but lack some of the understanding and skills required for their purchase and safe use.

A small but increasing number of people with learning disabilities living independently can, and do, develop substance misuse problems, and are sometimes targeted due to their vulnerability.

You were introduced to Fred earlier. Here is some further information about him.

Fred

Fred is very worried about attending GP appointments. His GP has told him for some time that he is drinking too much alcohol and this will affect his heart medication.

There are mixed messages for Fred – his mother and GP want him to stop drinking because of his heart condition and medication, but his brother and father collude with his drinking at parties and at the rugby. Fred does not want to stop drinking.

It is not clear how far Fred understands the risk alcohol poses to his health. His hearing impairment may mean that he does not always hear advice from health professionals.

Learning activity

As you can see, there are mixed messages here for Fred.

Reflect on this and identify arguments for both sides of this dilemma.

Arguments for curtailing Fred's drinking

Arguments for allowing Fred to continue with his drinking patterns as they are

You may have identified that Fred should stop drinking, as this affects his heart and medication. On the other hand, you might think that maintaining his social life with his dad and brother is important to him.

It may be that there is a compromise here. Perhaps, with help and support, Fred can maintain his social life of going to rugby with his dad and going out with Stephen and his friends, but be encouraged to drink less alcohol.

You will probably also be thinking about the fact that every one of us has the autonomy to make lifestyle choices about smoking or consuming alcohol, so should this be different for Fred?

Abuse, neglect and health inequalities

The **Equal Health Informed** DVD explains how people with learning disabilities may face additional risks from abuse and neglect that can impact on their health and well-being and lead to health inequalities.

Abuse and neglect can take many forms and may be caused by people working with, or in other relationships with, people with learning disabilities.

Forms of abuse and neglect include:

- **physical abuse**, such as being hit or injured on purpose
- **financial or material abuse –** theft, or misuse of money, property or personal possessions
- **emotional abuse** – intimidation, threats, humiliation, verbal or psychological abuse
- **sexual abuse** – involvement in sexual activity that is unwanted or not understood
- **neglect,** which can range from people not being provided with basics (such as food, clothing, attention or care) to failure to provide appropriate access to health and social services
- **discrimination** – treating people negatively because of their learning disability
- **restrictive practices** in health and social services, which can compromise people's liberty and human rights
- **misuse of medication** – giving medication inappropriately, overdosing or withholding medication.

You were asked in the DVD to think about how you might suspect that abuse was occurring, and it was suggested that you would look out for signs and symptoms of abuse that may include:

- injuries, bruises or weight loss
- behaviour changes, such as the person seeming to be withdrawn or depressed
- self-harm or a dishevelled or unkempt appearance.

You should be aware that this is not an exhaustive list, and the signs may include other things.

Remember

You need to act when you suspect someone is being abused or neglected by reporting it to your manager, even if you are not certain.

The Scottish Government has put in place a range of legislation to protect people with learning disabilities who may be subjected to abuse, neglect and inappropriate restrictions to their liberty.

Module 3

Promoting health and well-being for people with learning disabilities

Promoting equal health – health screening and health promotion

The law says that all health services must take the particular support needs of people with learning disabilities into consideration.

In this section, we encourage you to think about what extra things you need to do to ensure people with learning disabilities can access opportunities for health screening and promotion in an equal way. These are called **reasonable adjustments** and were explored in the DVD. You will recall this includes thinking about:

- making sure that information on health services is accessible to people with learning disabilities
- making sure that annual health checks occur and that health problems are treated
- ensuring people with specialist skills, such as learning disability liaison and community nurses, are available to support people in primary care and hospital settings
- giving people more time with doctors and nurses.

We developed your learning about these issues in modules 1 and 2 – you should reflect on the learning you undertook in these modules.

Improving access to health screening

You were introduced to Sheila and Nan earlier. Consider what is happening to Sheila now.

Sheila and Nan

Shortly after her 50th birthday, Sheila received her first invitation for bowel screening. Nan supported Sheila to collect the samples required.

If Nan had not been able to support Sheila with collecting the samples required, she may not have been able to benefit from bowel screening.

Learning activity

Think about the people with learning disabilities you work with.

List the health screening/checks they have.

Record your answers here.

You may have mentioned bowel screening, as described above, or:

- cervical smear tests
- breast screening.

These tests are usually carried out in community or primary care settings. There are also other checks we do ourselves at home, such as women examining their breasts and men examining their testes. Obviously, these health checks are equally important, and accessible information is available on how people with learning disabilities can be supported to carry them out themselves.

If you would like more information on easy-read guides that can help you support people to access and undertake health screening, you may wish to visit either the **FAIR** or **NHS Health Scotland** websites.

Module summary

We have looked in this module at a range of health and well-being issues that affect people with learning disabilities. We have explored some of the factors that can impact on the health and well-being of people with learning disabilities, including common physical health, mental health and wider well-being issues they may experience, and how you can support people with learning disabilities to maintain and improve their health.

You should now be able to:

1. appreciate the factors that can impact on the health and well-being of people with learning disabilities
2. describe some common physical health, mental health and well-being issues that may be experienced by people with learning disabilities
3. describe how people with learning disabilities can be supported to maintain their health
4. describe how health screening/promotion can be improved for people with learning disabilities
5. further explore how access to health services can be enhanced for people with learning disabilities to improve health equalities.

Your learning in this module will be further developed in the remaining modules of the resource.

Module 3

Promoting health and well-being for people with learning disabilities

Reflective account

Write a reflective account taking into consideration your learning from Module 3.

Below is a suggested structure you may find helpful in writing your reflective account.

What happened?

Identify and describe a situation or incident in which you were supporting a person with learning disabilities to maintain his or her health. When recalling this situation, you may wish to consider the following:

- the specific physical and/or mental health issues the person was experiencing.

Describe what you did or how you responded.

Describe the outcome of your actions or response.

So what does this mean?

How did you feel about the outcome of the support that you provided at the time?

What do you feel about that now, in light of your learning from the module?

What did you do that went well?

Do you think your actions helped to improve quality of life for the person you were working with?

What might you now do differently?

Now what will you do in the future?

How will this affect the way you work with people with learning disabilities in the future?

Would you act differently, or would you be likely to do the same?

What further learning do you need to undertake to enhance your understanding of learning disability that will help you to support people to achieve equal health?

You may want to record this using the **paper into practice** activity at the end of the module.

Paper into practice

From your learning in this module, make a note of:

- three new things you have learned about how you could support people with learning disabilities to maintain their health and well-being
- your current practice in relation to supporting people with learning disabilities with their care needs
- three changes you could make that you feel would enhance your approach to supporting people with learning disabilities with their health and well-being.

When you have completed your journey through this learning resource, return to your notes and check whether you have achieved the second and third points.

Make notes of your responses here.

Module 4

Supporting people with particular health needs

Module 4

Supporting people with particular health needs

Learning outcomes

By the end of this module you should:

1. recognise when people may be experiencing ill health
2. identify when people may be experiencing pain
3. describe the specific physical health, mental health and well-being issues that may be experienced by people with learning disabilities
4. explore how you would be able to work with people with specific health needs to promote their equal health.

Introduction

Previous modules have highlighted why people with learning disabilities may be at particular risk of health inequalities. It is not inevitable that people with learning disabilities will develop poor health, but they have additional issues that may increase the likelihood of physical, emotional, psychological and mental health problems.

People with learning disabilities will experience a similar range of illnesses as the general population, but some conditions are more frequent; these can be general conditions or specific genetic syndromes that may have caused the learning disability. Evidence shows that some physical, sensory and mental health needs of people with learning disabilities go unrecognised and unmet by healthcare services. This often has a negative impact on quality of life, health equalities and life expectancy.

In this module, we build on your previous learning by examining particular physical and mental health and well-being issues that people with learning disabilities can experience and which can influence their equal health. We also consider how you can support people who have these specific needs.

Please note it is beyond the scope of this resource to explore every health problem people may experience – our focus is on promoting equal health.

If you are working with people with learning disabilities who have been diagnosed with a particular health problem or are undergoing specific treatments, you should ensure you find out more about the conditions and treatments and how you can offer support.

Recognising ill health and pain

Recognising when people may be experiencing ill health

As a starting point, it is important that everyone involved in the life of the person with a learning disability is alert to the status of their physical and mental health. You will recall how the **Equal Health Informed** DVD highlighted how essential it is that people with learning disabilities have regular check-ups of, for example, their sight, hearing, dental and oral health to prevent health problems occurring. It is also important that they be supported to participate in health screening. The nature and degree of the person's learning disability needs to be identified to determine the level of support he or she may require to access preventative healthcare on a regular basis.

As we discussed in earlier modules, some people with learning disabilities may be less able to identify when they are unwell or to tell others about what they are experiencing, so it is important to look out for signs that the person might be experiencing health problems. This is vital if we are to ensure that people are not disadvantaged in their access to health services by the fact that they have a learning disability: it is also particularly important as the use of anticipatory or preventative measures can help prevent hospital admission.

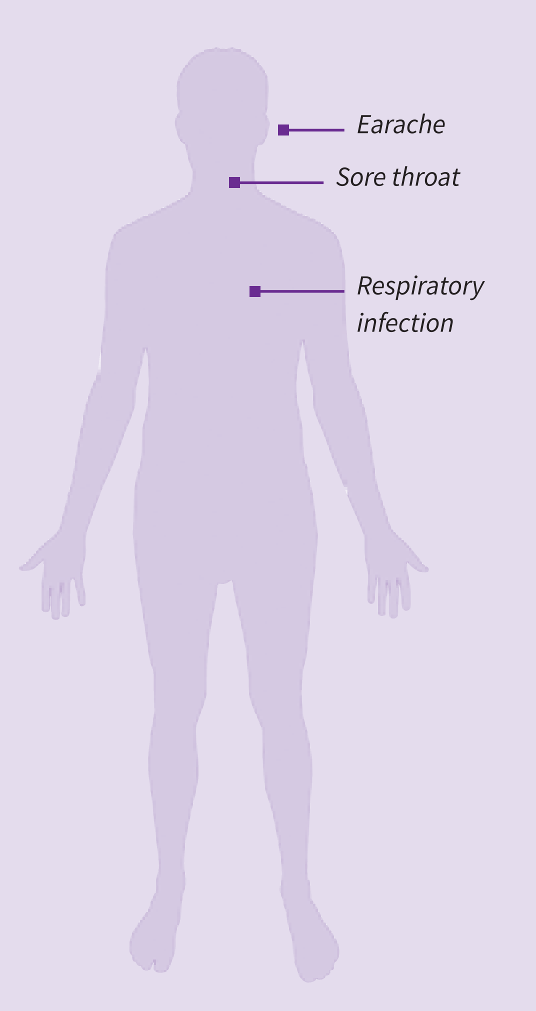
Really knowing the people you are working with is, of course, critical, as small changes may indicate that something is wrong.

You should try to identify easy ways to pick up on any issues as early as possible. This might include consideration of the following questions.

- Is the person complaining of pain?
- Is the person demonstrating the effects of pain (wincing or other bodily movements or simply holding themselves in a different manner)?
- Have the person's vital signs changed (this includes temperature, respiration and pulse)?
- Does the person have discharges from his or her eyes, ears or nose?
- Does the person have bruises or other marks on the body?
- Is the person maintaining weight?
- Has there been a change in mood or behaviour?

Learning activity

Look at the diagram of the body below. This can be used as an aide memoire in identifying the range of conditions that could be affecting the physical health and well-being of any person you may be working with. A good tip is to go through the body from head to toe. Write beside the diagram the things that you have identified. A few points have already been inserted to give you a start.



You may have identified sickness, diarrhoea, constipation, urine infections, joint pain and many more.

Recognising when someone might be in pain or distressed

We can use the **Disability Distress Assessment Tool (DisDAT)** when communication issues make it difficult to identify if a person with a learning disability is experiencing pain. It cannot directly identify pain, but DisDAT can help to identify distress when someone is unable to tell you how they are feeling. Each person will have their own ‘vocabulary’ of distress signs and behaviours and DisDAT can help with documenting signs, behaviours and cues when someone is content or distressed. It is NOT a scoring tool, but can help to put the distress into context by providing a checklist that suggests possible causes.

By capturing the views of all the key people in the person’s life, including staff, family, friends and carers, DisDAT enables consensus to be reached on what each behaviour signifies. It then helps to create a summary of the signs and behaviour specific to an individual that can easily be shared with other staff and teams.

Regular use of DisDAT can also provide a useful baseline assessment to use if someone subsequently becomes distressed. For more information, visit the **DisDAT** website.

Remember

If you feel the person you are supporting is unwell, in pain or experiencing distress, it is really important that you make other team members and your manager aware of your concerns.

Particular physical health issues and equal health

Eating and drinking difficulties for people with learning disabilities

Difficulties with eating, drinking and swallowing have a high prevalence among people with learning disabilities and can have serious implications for their health, safety and well-being. This can have serious repercussions, including the risk of experiencing severe health problems, or even death, if not appropriately assessed and managed.

People are at high risk of:

- aspiration (inhaling food or fluid into their lungs)
- dehydration
- choking (including death from choking)
- poor nutrition and weight loss
- poor oral health
- constipation.

Dysphagia

Dysphagia refers to difficulty in eating, drinking or swallowing. It can lead to malnutrition, dehydration, choking and reduced quality of life.

Many people with learning disabilities have signs and symptoms of swallowing difficulties, which include:

- difficulty placing food in the mouth
- inability to control food or saliva in the mouth
- difficulty initiating a swallow, coughing, choking
- frequent chest infections
- unexplained weight loss
- a bubbly or ‘wet’ voice after swallowing
- regurgitation.

Dysphagia should always be considered when someone is experiencing unexplained eating or breathing difficulties, changes in eating patterns, distress associated with eating, or recurrent chest infections.

Often, the more complex and profound the person’s disability, the more severe the dysphagia. Dysphagia might also be caused by less obvious factors like medications, polypharmacy and community-acquired infections. Asphyxia and respiratory-related mortality are known to be disproportionately high in people with learning disabilities.

Many people with cerebral palsy also suffer from chronic gastrointestinal problems such as gastro-oesophageal reflux disease (GORD), a common condition in which acid from the stomach leaks into the oesophagus.

Dysphagia and its potential consequences are often assessed and managed by a qualified dysphagia practitioner, typically a speech and language therapist. In your practice, you may find that you are best placed to notice and report any signs of swallowing difficulties: you can provide key information for assessments carried out by speech and language therapists. You may find the checklist overleaf a useful tool to help in your observations.

Does the person you are working with exhibit any of the following:	Yes/No
history of choking episodes	
coughing during and/or after meals	
history of frequent chest infections	
increased shortness of breath when eating or drinking	
dysarthria (difficulty speaking)	
'bubbly' voice quality	
failure to maintain weight	
slow eating and/or declining food	
regurgitation	

Treatments for dysphagia vary widely, from surgery to environmental changes that include use of specialised utensils, positioning the person in particular ways, and texture modification of food and fluids. Using texture modification for foods and thickened fluids to treat dysphagia has become increasingly controversial in recent years, with associated risks of dehydration, urinary tract infection, fever and pneumonia. It is important that you are aware of these risks if you are supporting someone who requires texture modification for foods and thickened fluids and that you report any concerns to your manager.

Dysphagia and respiratory tract infections

We introduced you to Emily earlier.

Emily

Emily is 30 years old. She lives in a care-home setting with 24-hour support. Her family visit her once a year on her birthday.

Complications at Emily's birth meant she was starved of oxygen for some time. She has cerebral palsy and quadriplegia. She is also blind and is totally dependent on staff to meet all her needs.

Emily does not have interaction with people apart from the staff who support her. She enjoys listening to music and reacts to things that make noises. Emily communicates using the words 'yes' and 'no' but has been assessed by staff as not being able to engage with any conversations.

Emily spends most of her time alone in her room. She has one hour of one-to-one activities and a short session with staff from the Royal National Institute of Blind People once a week. She has not been given a chance to socialise and seems to be very isolated. Emily has all her decisions made for her by staff in the unit.

Here is what has happened with Emily recently.

Emily has had difficulty in swallowing and, after assessment by a speech and language therapist, has been diagnosed with dysphagia. She has also had repeated respiratory infections and these are thought to be caused by her aspirating food and drink.

Learning activity

Emily has very few communication skills. List the things you may notice that would suggest she has a respiratory infection.

Record your answers here.

You may have included in your answer some of the symptoms of respiratory tract infections, which can include cough, sore throat, runny nose, nasal congestion, headache, low-grade fever and sneezing.

Emily's respiratory tract infection is thought to have been caused by aspirating food and drink. Aspiration is also known to cause or contribute to:

- chest infections and aspiration pneumonia
- long-term lung damage
- other lung conditions.

Respiratory disease is possibly the leading cause of death of people with learning disabilities, with rates much higher than for the general population. Around 40% of people with dysphagia will experience recurrent respiratory tract infections.

Learning activity

What actions would you take if you detect symptoms indicating someone might have a respiratory infection?

Record your answers here.

You probably identified that you would:

- keep a record of symptoms
- inform your manager immediately
- seek medical advice.

You should also be aware that if Emily continues to have respiratory problems because of her dysphagia, it is likely that she will need a further referral to a speech and language therapist, a dietician and a pharmacist, who may carry out a medication review for drugs that might be contributing to her swallowing difficulties.

When a person's swallowing mechanism is significantly impaired, it may no longer be safe to administer food, drinks and medication orally. Nutritional support may then be given via an enteral feeding tube. Different routes available for enteral feeding are:

- nasal routes: nasogastric (NG), nasoduodenal (ND) and nasojejunal (NJ) – tubes for nasal routes have a long fine bore and are generally used only on a temporary basis
- routes through the abdominal wall: percutaneous endoscopic gastrostomy (PEG) and percutaneous jejunostomy (PEJ) – these are shorter, wider-bore tubes that are inserted surgically directly into the gastrointestinal tract, making it less likely to block.

Most health boards have information about enteral feeding on their websites. If you wish to find out more, please visit your local health or joint integration board's website and key in 'PEG feeding'.

Other considerations related to eating and drinking difficulties

In addition to the risk of poor nutrition and weight loss associated with dysphagia in people with learning disabilities, it is also important to note that:

- people with Down syndrome are more likely to develop type 2 diabetes
- overeating is particularly associated with Prader-Willi syndrome (this is part of the syndrome)
- some people with learning disabilities eat inappropriate objects: this is known as pica.

Epilepsy and equal health

Epilepsy is one of the most common and persistent health problems in people with profound and multiple learning disabilities (PMLD), with over 60% affected. The more severe the developmental delay, the higher the risk of epilepsy. The risk is also increased if there is associated cerebral palsy. Epilepsy is often misdiagnosed because the symptoms resemble a number of other conditions.

Seizures, defined as a sudden electrical discharge in the brain causing alterations in behaviour, sensation or consciousness, are a key symptom of epilepsy. They are not only frightening for the person experiencing them, but also cause great anxiety for families and carers. Seizures can lead to injury and unexpected sudden death.

It is very important that families and carers have appropriate support to enable them to understand what is happening, recognise the symptoms and keep a detailed history of the person's epileptic events. This history, which could include video recordings from a mobile phone, is essential in supporting health professionals to make the correct diagnosis and prescribe the right treatment.

Epilepsy is usually controlled with appropriate medication, but control can be more difficult for people with PMLD due to the severity of the epilepsy and the effects of other health problems. Epilepsy medication can have severe side-effects, so it is important to achieve a balance between reducing the frequency and severity of seizures and maintaining, or improving, quality of life for individuals, their families and carers.

You may find the following information a useful reminder of what to do when someone you are working with has epilepsy.

Module 4

Supporting people with particular health needs

When a seizure starts, DO:	When a seizure starts, DO NOT:
■ note the time	■ put anything in the person's mouth
■ clear a space around the person	■ restrain or restrict movement during the seizure
■ cushion the head to prevent head and facial injury	■ give anything to eat or drink
■ loosen tight neckwear	■ move the person unless he or she is in immediate danger
■ loosen any chest and leg safety straps on wheelchairs	
■ remove spectacles, if worn	
■ turn on side if possible, to aid drainage (recovery position)	
■ reassure others and explain what you are doing	

Treatment for epilepsy

Anti-epileptic drugs are available to treat different types of seizures and syndromes. People with PMLD may not be able to be completely seizure-free with the use of just one drug, and a combination is usually prescribed. It is often a case of trial and error, with different dosages of drugs tried until the combination that has the best result is found. This can be a long process, as introducing and withdrawing medication has to be done slowly and in a controlled way.

Factors that can trigger seizures include:

- missed medication
- illness/infections (such as urinary tract infections)
- lack of sleep
- heat
- stress (including that caused by constipation or pain)
- the menstrual cycle.

Remember

A care plan for use by everyone involved in supporting the person should be drawn up in consultation with the person's GP and/or specialist service. It is important that you are familiar with this so you can take appropriate actions when required.

The care plan should include:

- a record of triggers that cause seizures and seizure warning signs
- descriptions of seizures, including length, frequency and recovery
- pattern – for instance, whether they occur mostly at night or during the day, or are linked to events such as menstruation
- prescribed medication
- seizure-recording sheets (including annual charts)
- who records the seizure
- protocols (see below)
- who should be contacted afterwards
- all relevant correspondence from GP, hospital and other services.

Emergency medication

Most seizures stop on their own without intervention within five minutes. Status epilepticus is a seizure lasting for 30 minutes or longer, or a cluster of shorter seizures going on for 30 minutes or more with little or no recovery in between. It is a medical emergency because the longer a seizure lasts, the less likely it is to stop on its own and respond to emergency medicines. Status epilepticus can lead to brain damage, or even death. Emergency treatment should be sought or given by carers.

Remember

Status epilepticus during a tonic-clonic seizure is a medical emergency.

Quick intervention is needed when a seizure does not stop on its own. People who are known to have prolonged seizures are commonly prescribed emergency or rescue medication. This can be administered in the community by family or carers, allowing quick intervention and often preventing transfer to hospital.

Two preparations are commonly used – diazepam rectal tubes and midazolam buccal liquid. They are usually administered when a seizure has continued for five minutes to prevent status epilepticus and improve the outcome. Although rectal diazepam has proved effective, for many people and their family/carers it has become increasingly unpopular because of its route of administration, variable absorption and adverse effects. Buccal midazolam liquid is therefore increasingly being used.

Rescue medication protocols for rectal diazepam and buccal midazolam can be viewed on the **NHS Scotland Toolbox for Management of Epilepsy in People with a Learning Disability** website, which we encourage you to visit.

Sensory issues and equal health

Sight

One in three people with learning disabilities has a sight problem, many of which could be correctable. Up to 90% of people with Down syndrome and 70% of those with cerebral palsy may have significant sight impairments.

Many people have lived for years, even their whole lives, without knowing they have a sight problem, and families and carers may not know how to recognise difficulties. Unrecognised or uncorrected sight problems can make it difficult for people to learn new skills, or do things they used to enjoy. This might be put down to the person's learning disability rather than a correctable sight problem, such as a cataract or simply the person's eyesight deteriorating with age.

Sight helps us to:

- communicate with others
- develop and maintain relationships
- move safely around and make sense of our world
- take part in leisure and recreation activities
- learn skills and take part in education and work activities
- maintain our independence.

Undiagnosed or unnoticed sight problems can lead to people becoming:

- distressed and angry
- anxious and frustrated
- withdrawn and frightened
- deskilled and demotivated
- prone to self-harming (eye-poking or self-injury to the head and eyes).

These are all issues that will contribute to potentially unequal health for people with learning disabilities. Accessible information and skilled support from others can prevent them from occurring and ensure that people with learning disabilities can access quality eye care.

Learning activity

A person with a learning disability may not be able to tell you that he or she has a sight problem.

What signs that the person is having visual problems could you look out for?

Record your answers here.

You might have mentioned some of the following:

- the person's eyes might look sore or blood-shot, or cloudy
- the person might start squinting or moving his or her head to 'odd' positions when looking at, or looking for, things
- the person might start to become disoriented
- he or she might no longer enjoy TV or looking at photos
- familiar faces or places may be unrecognised
- the person might become tentative or fearful in twilight or in shadows, or be disoriented in bright sunlight.

If you are concerned that someone you are working with is affected by sight issues, you should alert your manager, who can arrange an appointment with an optician, optometrist or ophthalmologist.

Hearing

The term ‘hearing impairment’ applies when an individual’s hearing is affected by a physical condition or injury. People can be born with hearing loss, or it may develop with age. Around 40% (exact estimates vary) of adults with learning disabilities experience moderate-to-severe hearing loss. In some cases, it may exacerbate the effects of an individual’s learning disability.

Behaviour caused by the person’s hearing loss can often be considered part of the learning disability if the hearing loss is unrecognised or undiagnosed. Untreated hearing loss can contribute to delayed speech and language development, difficulties with learning and problems communicating with others. Early diagnosis is therefore vital, especially for people who may already experience difficulties in these areas. Hearing problems are particularly common among people with Down syndrome and, as with the general population, this can become more common and more extensive as people age.

You will remember that we were introduced to Fred and his family in earlier modules.

Fred, Joan and Stephen

Fred, who is 19, lives at home with his mother Joan and his brother Stephen. They live in a small house on a council housing estate. Fred left school at 17 and went to college until he was 18. He is currently unemployed. Joan relies on benefits for her income and Stephen, aged 26, is also unemployed. While Fred does not have any friends of his own and can be quite anxious in unfamiliar social situations, he likes to go to the pub with his brother and his friends.

Fred has a mild learning disability and has been diagnosed as autistic. He has DiGeorge syndrome, which has led to him having heart problems, for which he needs to take medication, and impaired hearing.

Fred is very worried about attending GP appointments. His GP has told him for some time that he is drinking too much alcohol and this will affect his heart medication.

There are mixed messages for Fred – his mother and GP want him to stop drinking because of his heart condition and medication, but his brother and father collude with his drinking at parties and at the rugby. Fred does not want to stop drinking.

It is not clear how far Fred understands the risk alcohol poses to his health. His hearing impairment may mean that he does not always hear advice from health professionals. Fred’s hearing problems might also be contributing to his anxiety in social situations and he is using alcohol to manage this.

Learning activity

What do you think should be done about Fred’s hearing impairment?

Record your answers here.

You may have mentioned that Fred would benefit from a hearing test and possibly would be suitable for hearing aids. If this was the case, Fred may then be in a better position to actually hear what the doctor is saying about his alcohol consumption and feel less anxious in social situations.

Help and advice on hearing loss can be accessed at the **Action on Hearing Loss** website, or you may wish to access the **SENSE** website: SENSE is a national charity that supports and campaigns for children and adults who are deaf, blind or have associated disabilities.

Supporting continence and equal health

People with PMLD are extremely likely to have continence issues due to impaired neurological development, other medical problems, the effects of medication and dietary issues. Emotional and behavioural issues can also impact on a person’s bowel and bladder control.

Continence is both a health and quality-of-life issue. It is therefore extremely important that people with PMLD get the right kind of individual support to meet their circumstances, while upholding their dignity and privacy and maintaining good health. All people with continence problems are entitled to a continence assessment to identify the underlying causes and contributory factors.

Once a diagnosis is made, a treatment plan can be developed. The most suitable method of management for many people with PMLD is through containment, using pads that are available from continence services.

The lack of suitable changing facilities in public toilets in the community is one of the most restrictive practical problems preventing people with PMLD from going out and about and participating in everyday activities. This results in:

- families changing their daughters or sons on toilet floors, which is undignified and unhygienic
- heavy lifting by the carers, with the potential to cause serious damage to their backs
- families opting to stay at home, which increases isolation and lack of stimulation.

The absence of suitable public toilets means that people with complex disabilities who need assistance cannot take part in activities such as shopping, going out for a meal or attending a sporting event. Promoting a More Inclusive Society (PAMIS), the organisation that supports people with PMLD, has campaigned for ‘changing-places toilets’ for several years. A number of these toilets now exist in Scotland, and the **PAMIS** website details exactly where they are so people can plan in advance.

Postural care and equal health

A significant proportion of people with learning disabilities have additional physical issues that affect their mobility. For many, postural support can be critical in reducing pain and discomfort and creating the optimum situation for getting the best out of life.

Postural care is defined as support to protect someone's body shape by using the right equipment and positioning techniques. This can be done to ensure protection and help restore body shape. The lack of good postural care can cause premature death. It is extremely important that positioning or postural care is done properly, particularly for people with PMLD.

Common difficulties experienced by people who do not have access to postural care include hip pain, structural problems at the hip, seating difficulties, communication problems, swallowing, feeding or digestive difficulties, increased risk of chest infection and skin problems, and pain and discomfort.

Postural care is very simple and gentle. People are at risk of developing changes in body shape if they find it difficult to move independently, spend lots of time in a limited number of positions, experience other difficulties such as hypermobility (which means they have very flexible joints), or have low muscle tone. Children are at greater risk than adults because they are growing so quickly.

The gold standard for assessment of body shape is the Goldsmith Indices of Body Symmetry, which is an objective and validated measure of a person's structure and movement.

Postural care is a fundamental aspect of a person's physical healthcare. The way in which the body responds to the effects of gravity is predictable, so we are able to use equipment and positioning strategies to prevent changes in body shape and their associated secondary complications.

Some people need postural care for a short period of time (when recovering after surgery, for example), but others will need it for longer periods, perhaps their whole life, to be protected from the harmful effects of gravity.

If you have concerns about postural care for the people you support, an occupational therapist or physiotherapist may be able to offer specialist advice and support in relation to seating and use of equipment.

For further information, we recommend that you access the **Postural Care learning byte** on the **NES** website.

Palliative and end-of-life care for people with learning disabilities

Palliative care is an approach to working with and caring for a person with a life-limiting or terminal condition. It supports a person-centred and equality approach and concentrates on the individual rather than his or her specific disease. It gives equal focus to the psychological, physical, spiritual and social aspects of the person's life and aims to improve quality of life for the person and family, enabling him or her to die with dignity and in a place of their choosing.

The term 'palliative care' is also used to describe specialist care and interventions required as the person approaches the end of life. This may also be referred to as 'end-of-life care' and aims to make the person comfortable and ensure his or her needs and wishes are respected as the end of life approaches.

Working with people with learning disabilities and supporting them to live well includes supporting them to die well. We need to ensure the care, treatment and support they receive at the end of life reflects their decisions and expressed wishes and preferences. The development of personal support plans and advance plans should provide the person with an opportunity to discuss and record his or her wishes and preferences. Everyone working with the person should be aware of the plan and the wishes documented in it, and use these to inform care and support at the end of life.

There is evidence to suggest that in the final months of their lives, people may experience symptoms such as pain, depression, incontinence, constipation, appetite disturbance, breathlessness, swallowing difficulties, weight loss, dehydration and pressure ulcers.

Everyone working with the person should be aware of the range of changes and symptoms the person may experience at the end of life and communicate sensitively with the family and carers.

Emotional, psychological and mental health issues and equal health

Behaviours perceived as challenging and equal health

Some people with learning disabilities display behaviours that staff and others perceive as challenging. Behaviour is often used in everyday language to refer to 'good' or 'bad' behaviour, as if our behaviour is only part of what we do. In behavioural terms, 'behaviour' refers to everything we say or do. This means:

- a person is perceived as 'behaving' all of the time
- activity is often considered as being the same as behaviour
- a person is behaving even when he or she is doing nothing.

'Challenging behaviour' has become part of everyday language in the field of learning disability. Behaviour can be perceived or described as 'challenging' for a variety of reasons, and behaviour that may be appropriate in one setting may not be so in another. This is reflected in the following definition from the Royal College of Psychiatrists:

> **'Behaviour can be described as challenging when it is of such frequency, intensity or duration as to threaten the quality of life and/or the physical safety of the individual or others and is likely to lead to responses that are restrictive, aversive or result in exclusion.'**

We use the term 'behaviours perceived as challenging' in this section to place an emphasis on services' ability to meet people's needs and move away from the view that the difficulties are an intrinsic part of the person.

People with learning disabilities who sometimes behave in a way that is perceived as challenging are at risk of experiencing a number of health inequalities, including:

- social isolation and social exclusion
- stigma and discrimination
- restrictive practices that violate their human rights
- a failure to detect both physical and mental health problems, with changes and issues being attributed to their 'challenging behaviour' (this is called diagnostic overshadowing)
- over- and inappropriate use of medication
- greater risk of abuse and neglect in the health and social care system.

You will recognise some of these factors when you reflect back on Bobby, who we introduced at the start of the resource and whose story we developed in later modules.

Learning activity

Think about things that might cause people to behave in ways that others find challenging.

Note your thoughts below.

Many personal and environmental factors can impact on people's behaviour.

Personal factors include:

- **health** – physical and mental health problems can affect behaviour; think about the last time you were unwell, and imagine if you couldn't explain to others how you were feeling
- **communication** – most behaviour perceived as challenging can be viewed as having a communicative function, in that a person is trying to express a need ("I am bored/hungry/in pain")
- **personality and character** – some people are laid back and take things in their stride, while others are more anxious and easily frustrated
- **past experiences** – these can shape how we respond to current situations because we have learned what works for us: for instance, we put slippers on if we get up during the night as we've learned to do this to avoid stepping on the cold floor in bare feet.

Environmental factors include the following.

- **Choice and control** – do people have choice and control over their environment and how they spend their time? How might you behave if you had little choice or control in your life?
- **Physical environment** – is it too noisy with little personal space, or a nice, warm and pleasant place to be? Would you like to live there?
- **Social interactions** – do workers demonstrate good values and attitudes? Are interactions between people good? Is there a nice balance of activity and relaxation?
- **Communication** – do people use the right methods of communication to help the person understand them and help them to understand the person?

Remember

Understanding why a person behaves in a certain way is complex, but taking a person-centred approach to understanding the behaviour from the person's perspective can help us to provide the right support.

Many positive approaches have been developed to help us understand why people might be behaving in a certain way and support those whose behaviours are perceived as challenging. These include:

- Positive Behavioural Support
- Active Support.

If you are involved in supporting people whose behaviour is perceived as challenging, you should undertake further learning through NES resources

Positive Behavioural Support: a learning resource and **Improving Practice: supporting people whose behaviour is perceived as challenging**. You can access both resources on the **NES** website.

Mental health issues and equal health

People with learning disabilities experience the same mental health problems as the general population, but with higher prevalence. Mental health problems in the learning disability population (sometimes referred to as a dual diagnosis) can have a huge impact on their general well-being, personal independence and quality of life, as well as having an effect on their family and carers.

Everyone is different, and mental health problems present in many ways. People with learning disabilities, however, will often not recognise their own symptoms or be able to report or describe their feelings to the GP. Instead, it is usually a family member or carer who would first raise concerns that an individual may be showing signs of a mental health problem.

Let us reconsider Donald, who you were introduced to earlier.

Donald

Donald is 25 and lives with his family. He works in a local supermarket three days a week stacking shelves and helping out with the trolleys. He enjoys his work and gets on well with the other staff. He is very close to his father, who is retired, and they spend a lot of time together during the week doing various activities they both enjoy. He also has a network of friends and meets them at a ‘social club’ organised by a local voluntary organisation twice a week.

Donald has Down syndrome and is seen to have a moderate learning disability. He also has a congenital heart defect associated with his condition. He sometimes has some difficulty in making choices and expressing himself, which he can find distressing.

Things have changed recently for Donald.

Sadly, Donald’s father has died suddenly. This has understandably devastated Donald, and he has taken time off work and stopped going to his social club.

Three months after his dad’s death, Donald’s mother is getting worried, as he rarely comes out of his room, is not sleeping well or eating properly and has lost weight. When she manages to communicate with him, he is tearful and anxious.

Learning activity

Think about Donald.

What are the signs that might indicate he is experiencing mental health issues?

What should you do about this?

How might this impact on his ability to achieve equal health?

Record your answers here.

In relation to signs, you will probably have noted that Donald is not eating or sleeping well, is isolating himself in his room, has taken time off work and stopped going to his social club. You will also have noted that he seems low in his mood and anxious, and appreciated that it is understandable, given his recent life events.

So what should you do? Here are some suggestions:

- using the person-centred approaches we have previously discussed, you could support Donald to express his feelings
- you could engage with Donald's mum to get her perspective on the situation and actively involve her
- you should immediately discuss any concerns with your manager
- you could suggest that Donald sees his GP.

On the impact on his ability to achieve equal health, you will probably have identified that he might:

- lose his job and friendships
- become socially isolated
- have poorer physical and mental health.

All of these will have an impact on his equal health.

Supporting people with loss and bereavement

The emotional needs of people with learning disabilities, particularly in relation to death, dying and bereavement, often remain neglected. Many people with learning disabilities have to cope with death, dying and bereavement without being fully informed about what is going on.

In Donald's case, as we have seen above, he has recently lost a parent who was involved in caring for him and who provided him with a significant point of community contact through the social club. It is still the case that the reactions of people with learning disabilities are sometimes not acknowledged: Donald's mum may be struggling with her own grief and may be unsure about how to console Donald. There may also be times when diagnostic overshadowing might lead to grief reactions being seen as a sign of other problems. This can be a particular problem when someone is unable to communicate verbally.

We have discussed in this section of the module some emotional, psychological and mental health issues in relation to promoting equal health for people with learning disabilities. If you want to explore these issues in more depth, we recommend you access the learning resource **Thinking about me? Essential psychological care for people with learning disabilities**, which you can access through the **NES** website.

Module 4

Supporting people with particular health needs

Module summary

In previous modules, we have highlighted why people with learning disabilities may be at particular risk of health inequalities. It is not inevitable that people with learning disabilities will develop poor health, but they have additional issues that may increase the likelihood of physical and mental health problems.

People with learning disabilities experience a similar range of illnesses as the general population, but some conditions are more frequent; these can be general conditions or specific genetic syndromes that may have caused the learning disability. Evidence shows that some physical, sensory and mental health needs of people with learning disabilities go unrecognised and unmet by healthcare services. This often has a negative impact on quality of life, health equalities and life expectancy.

This module has built on your previous learning by examining particular physical and mental health and well-being issues that people with learning disabilities can experience, and how this can influence their equal health. We have also considered how you can support people who have these specific needs.

You should now be able to:

1. recognise when people may be experiencing ill health
2. identify when people may be experiencing pain
3. describe the specific physical health, mental health and well-being issues that may be experienced by people with learning disabilities
4. explore how you would be able to work with people with specific health needs to promote their equal health.

It is beyond the scope of this resource to explore every health problem people may experience – our focus is on health equalities. If you are working with people with learning disabilities who have been diagnosed with a particular health problem or are undergoing specific treatments, you should ensure you find out more about the conditions and treatments and how you can offer support.

Module 4

Supporting people with particular health needs

Reflective account

Write a reflective account taking into consideration your learning from Module 4.

Below is a suggested structure you may find helpful in writing your reflective account.

What happened?

Identify and describe a situation or incident in which you were supporting a person with a learning disability through particular physical or mental health situations such as those explored in this module. When recalling these situations, you may wish to consider the following:

- the specific issues the person was experiencing
- strengths- and asset-based approaches.

Describe what you did or how you responded.

Describe the outcome of your actions or response.

So what does this mean?

How did you feel about the outcome of the support that you provided at the time?

What do you feel about that now, in light of your learning from the module?

What did you do that went well?

Do you think your actions helped to improve quality of life for the person you were working with?

What might you now do differently?

Now what will you do in the future?

How will this affect the way you work with people with learning disabilities in the future?

Would you act differently, or would you be likely to do the same?

What further learning do you need to undertake to enhance your understanding of learning disability that will help you to support people to achieve equal health?

You may want to record this using the **paper into practice** activity at the end of the module.

Module 4

Supporting people with particular health needs

Paper into practice

From your learning in this module:

- make a note of three new things you have learned about how you could support people with learning disabilities in relation to specific physical and mental health issues
- reflect on your current practice in relation to supporting people with learning disabilities with their specific physical and mental health issues
- make a note of three changes you could make that you feel would enhance your approach to supporting people with learning disabilities.

When you have completed your journey through this learning resource, return to your notes and check whether you have achieved the second and third points.

Make notes of your responses here.

Module 5

Human rights, learning disabilities and equal health

Module 5

Human rights, learning disabilities and equal health

Learning outcomes

By the end of this module you should:

1. understand a human rights-based approach
2. apply a FAIR approach to decision-making when considering how best to reduce the risk of health inequalities within a human rights context
3. understand the principles of capacity and consent and how they apply to your role to inform and develop your practice
4. understand the principles and provisions of legislation in place to protect people with learning disabilities, their families and carers' rights and choices, and how this should inform your practice
5. understand when people with learning disabilities may be experiencing neglect, harm or abuse and how they should be protected.

Introduction

People with learning disabilities, their families and carers have the same rights as everyone else in society, and we need to empower, enable and support them to exercise their rights. In this module, we explore what rights are and our duty to ensure not only that the dignity and civil and legal rights of people with learning disabilities are respected, but also that they are provided with the level of assistance they want and need to participate in decisions that affect their well-being. We look at how a FAIR approach to decision-making can be used to protect the rights of people with learning disabilities so they can maintain their health and well-being.

We also explore the issues of capacity and consent and how this applies to your role to inform and develop your practice, alongside the principles and provisions of legislation to protect people's rights and choices. Finally, we look at situations in which people with learning disabilities may be experiencing neglect, harm or abuse and how they should be protected.

Module 5

Human rights, learning disabilities and equal health

What are rights?

Rights can mean different things to different people in different cultures and countries. In Scotland and the UK, rights are something people expect to enable them to have an acceptable quality of life. They are not about privileges or being allowed to do something – they are a 'given' and are generally thought of as protected.

We would expect that people with learning disabilities, their families and carers would experience these same rights. As we have seen in earlier modules and in the **Equal Health Informed** DVD, however, people with learning disabilities unfortunately can experience stigma, abuse, discrimination, mistreatment and a lack of access to appropriate services to meet their needs. Legislation in Scotland enables all workers to have a role in ensuring people's rights can be better protected to maximise their potential for a good quality of life and equal health.

The Human Rights Act 1998

The Human Rights Act came into force in October 2000 and has made rights from the European Convention on Human Rights enforceable in British courts.

Human rights are rights and freedoms to which everyone is entitled. The Human Rights Act originated from concerns for people being denied their basic rights during the Second World War and provides a common understanding of what everyone's rights are.

There are 16 basic rights that apply in Scottish law, all of which have been taken from the European Convention on Human Rights. The 16 basic rights cover a range of areas, from freedom from inhuman treatment to everyday issues like respect for privacy and family life. The Convention recognises that while rights cannot be taken away (except in extreme circumstances), most are balanced against the rights of other people (such as the right to respect for private life and family) while others are considered absolute, such as the right to life.

The principles underpinning the Human Rights Act are:

- equality
- respect
- dignity
- fairness
- autonomy.

Rather than detailing all 16 rights, here are some practice examples that relate directly to people with learning disabilities that will help you to recognise these in your practice and workplace.

Examples of human rights that may be disregarded in practice

The right not to be treated in an inhuman or degrading way:

- leaving a person in soiled or unchanged clothing or bedding
- repeated use of restraint to prevent a person leaving a hospital, care home or residential setting because there is insufficient staff to engage the person in meaningful activity
- staff working with people in their own home, hospital, care home or residential setting not protecting them from assault by others.

The right to respect for private and family life, home and correspondence:

- a person not being given any choice about where he or she wishes to live, which reduces or severs contact with family and friends
- staff working with people in their own home, hospital, care home or residential setting who are controlling the person's mail, phone calls etc. without authority
- imposing restrictions on with whom people can develop friendships.

The right to freedom or liberty:

- detaining a person in hospital who lacks capacity to consent to admission and without using legal process
- a person being continuously supervised and confined to a particular part of his or her own home, hospital, care home or residential setting
- a person constantly verbally expressing a wish to leave a hospital, care home or residential setting and sedation/medication being used frequently to control the behaviour.

The right not to be discriminated against:

- a person not being given access to medical treatment or community care services because he or she has a learning disability
- information or options being given in a way that is inaccessible to the person
- a person being patronised and ignored when asking for assistance with personal care.

Module 5

Human rights, learning disabilities and equal health

Learning activity

Reflect on your own work environment and practices in relation to the examples of human rights that may be disregarded for people with learning disabilities and which may then have an effect on their health and well-being.

☐ Can you identify any risks or examples that might suggest the people with learning disabilities you are working with may have their human rights disregarded?

☐ What changes or improvements could you make to contribute to protecting the rights of a person with a learning disability and therefore increase his or her health and well-being?

Record your answers here.

Scotland's strategy for people with learning disabilities, **The Keys to Life**, was published in 2013, with an implementation framework following in 2015. The implementation framework aims to involve a range of partners and stakeholders in delivering change and commits to using human rights-based delivery methods, including the **PANEL** and **FAIR** approaches (see overleaf).

The framework sets out the Scottish Government's vision for people with learning disabilities in Scotland:

> **"… that all citizens of Scotland who have learning disabilities live longer, healthier lives; are supported to Participate fully in all aspects of society; Prosper as individuals and are valued contributors to a Fair and equal Scotland."**

The **PANEL** (Participation, Accountability, Nondiscrimination and equality, Empowerment and Legality) principles, which you were introduced to in the DVD, uphold the rights of everyone to person-centred care and support.

The PANEL principles	
Participation	Everyone has the right to participate in decisions that affect them. Participation must be active, free and meaningful and give attention to issues of accessibility, including access to information in a form and a language that can be understood.
Accountability	Accountability requires effective monitoring of human rights standards. For accountability to be effective, there must be appropriate laws, policies, administrative procedures and mechanisms of redress to secure human rights.
Nondiscrimination and equality	A human rights-based approach means that all forms of discrimination must be prohibited, prevented and eliminated. It also requires the prioritisation of those in the most vulnerable situations who face the biggest barriers to realising their rights and well-being.
Empowerment	People should understand their rights and be fully supported to participate in the development of policy and practices that affect their lives. People should be able to claim their rights where necessary.
Legality	The full range of legally protected human rights must be respected, protected and fulfilled. A human rights-based approach requires the recognition of rights as legally enforceable entitlements and is linked to national and international human rights law.

Any proposed measures to reduce the impact of exposure to determinants of health inequalities should be implemented in a manner that is consistent with a human rights-based approach and with the person’s agreement, where he or she has capacity to give informed consent. Where decisions are made on behalf of a person who lacks capacity, it is of paramount importance that the decision-maker takes account of the need to respect, protect and fulfil the person’s human rights.

Module 5

Human rights, learning disabilities and equal health

A FAIR approach to promoting equal health

It is not enough to simply recognise that a person is at risk of serious health inequalities. Staff who provide care and support must also do something to reduce the risk.

Autonomy and dignity are always paramount when applying a human rights-based approach to reducing health inequalities. Compelling people to change their lifestyle could arguably promote equal health – we could restrict people's ability to smoke or drink alcohol and could try and make them take part in regular exercise, for instance – but the loss of autonomy and respect for the right of people to make their own choices could detract from their well-being more broadly.

The Scottish Human Rights Commission (SHRC) launched Scotland's National Action Plan for Human Rights in 2013 and the human rights-based 'FAIR' approach. The central role of any human rights-based approach is to ensure that people's dignity is at the heart of decision-making. Using the FAIR approach can provide a practical means of reaching balanced, right and just solutions in difficult situations.

The FAIR approach has four steps.

Establishing the facts

The first step in applying the **FAIR** approach involves establishing the key pertinent facts regarding a person's current situation. These questions help establish the facts.

- What is the experience of the person?
- Is the person being heard and, if not, does he or she require support to do so?
- What are the important facts to understand?

Analysing the rights at stake

Having established the key facts, an analysis should be developed to identify the human rights that are potentially at risk. These questions help with the analysis.

- What human rights or issues are at stake?
- Is the right to life or the right not to be subjected to inhuman or degrading treatment at stake? If so, these rights are absolute and cannot be restricted.
- Can the right be restricted? What is the justification for restricting the right?
- Is the restriction on the right 'proportionate' (that is, is it the minimum necessary restriction used to meet the aim)?

Identifying responsibilities

The FAIR approach then requires the development of an action plan for implementing the required changes or interventions. This should include details of the specific area for improvement, what the improved situation will look like, who is responsible for making it happen, and how progress will be reviewed. These questions help with identifying responsibilities.

- What changes are necessary?
- Who has responsibilities for helping to make the necessary changes?

Reviewing actions taken

This is the last stage of the FAIR approach and involves examining whether the actions taken have actually made a difference. These questions help with reviewing actions.

- Have the actions taken been recorded and reviewed?
- Has the individual affected been involved?

Adapted from the SHRC ***Care About Rights – thinking it through*** *FAIR flowchart.*

We will now explore how a FAIR approach could be used by applying it to Bobby's situation. Bobby's story was introduced at the start of the resource and developed in later modules.

Bobby

Bobby lives in supported accommodation with two other men. Until recently, he attended a day placement. He enjoys music, dancing and watching football.

Bobby sometimes displays behaviours perceived as challenging for the staff team: this is one of the reasons he is not attending the day placement at the moment and is now spending most of his time in his home.

Staff supporting Bobby have noticed that some of his behaviours, which include self-injury, aggression and destruction of property, are increasing. Bobby does not like noise or lots of people around him. He cannot communicate verbally and has no augmentative communication system (a system used to supplement or replace speech using, for example, symbols instead of words) in place.

Staff are restricting his movement in the house because of these behaviours and have had to physically restrain him on some occasions. He has also had emergency medication to try and manage his behaviour and to keep Bobby, the staff and other housemates safe.

Learning activity

Work through the key FAIR questions to apply a FAIR approach to improving Bobby's situation. In particular, think about this in relation to Bobby's health, drawing from your learning in previous modules.

Establishing the facts

Analysing the rights at stake

Identifying responsibilities

Reviewing actions taken

In applying the FAIR approach, your answers may have included the following.

Establishing the facts

- Bobby sometimes displays behaviours perceived as challenging for the staff team.
- He is not attending the day placement at the moment.
- He is now spending most of his time in his home.
- Some of his behaviours, which include self-injury, aggression and destruction of property, are increasing.
- He cannot communicate verbally.
- Staff are restricting his movements.
- He is being physically restrained.
- Emergency medication is being used.
- Staff are not recognising or responding to his needs.

Analysing the rights at stake

Two rights are at stake.

- The right to freedom or liberty: this right is being infringed, but is not an absolute right. Staff may be reacting to protect themselves and others, and may also be trying to protect Bobby from harm. The restriction is disproportionate and his needs have not been assessed.
- The right not to be treated in an inhumane and degrading way: this right is an absolute and cannot be restricted.

Identifying responsibilities

- Bobby needs a full physical and mental health assessment.
- He needs referral to speech and language therapy to identify if improvements can be made in his communication.
- There needs to be a full environmental assessment.
- The rationale for recommencing the day placement needs to be identified.
- The policies on restricting movement, physically restraining people and use of emergency medication need to be examined.
- A positive behaviour and active support plan needs to be in place (this was mentioned in Module 4).

The manager has responsibility for ensuring that these actions are taken forward and that all staff act according to the plans put in place.

Reviewing actions taken

- Bobby is involved in the planning process and the plans are recorded.
- A full review will have been carried out to identify if the plan has actually made a difference to Bobby’s health and well-being.

For people with learning disabilities, the FAIR approach provides a useful framework for:

- developing a factual understanding of a person's situation and factors that predispose him or her to serious health inequalities
- understanding the impact of the situation in terms of possible infringement of specific human rights
- considering whether any restrictions represent a proportionate response to achieving a legitimate aim
- identifying what changes are required and desirable and who is responsible for making them happen
- reviewing actions taken to respect, protect and enable people to fulfil their human rights.

To further develop your learning about the FAIR approach and human rights, we would encourage you to visit the SHRC **Care About Rights** website.

How the law in Scotland helps to protect people's rights

Legislation aimed at protecting rights tends to be developed as a result of concerns that individuals and particular groups of people are at greater risk of having their rights denied. Such groups include people with mental health problems, people with learning disabilities and people with dementia. We cannot assume, however, that because a person has a particular need, health issue or disability that he or she cannot exercise rights and choices.

The law in Scotland assumes that every adult has a right to, and is capable of, making all decisions affecting their lives. Deciding someone is not able to make decisions or protect their own interests can be extremely complex.

Legislation in Scotland that may be used to protect the rights of people with learning disabilities include:

- The Human Rights Act 1998
- Adults with Incapacity (Scotland) Act 2000
- Mental Health (Care and Treatment) (Scotland) Act 2003
- Adult Support and Protection (Scotland) Act 2007
- Equality Act 2010.

These laws on their own do not protect people, but create a framework in which organisations and individual workers are legally required to provide services to a defined standard. Each Act can be used on its own to protect a person, or they can be used together when needed. As changes and amendments to legislation may occur over time, it is important to check the **Scottish Government** website.

We are not able to explore all of the Scottish legislation in place to protect the rights of people with learning disabilities in this module, but will look at specific issues in relation to legislation and health equalities for people with learning disabilities.

The Mental Welfare Commission for Scotland ensures that care, treatment and support are lawful and respect the rights and promote the welfare of people with mental illness, learning disabilities and related conditions.

The Commission provides a wealth of information, guidance and best practice statements and also reports of their visits to services and investigations they have undertaken.

We would encourage you to visit the **Mental Welfare Commission for Scotland** website to learn more about protective legislation in place in Scotland.

Adults with Incapacity (Scotland) Act 2000

The Adults with Incapacity (Scotland) Act 2000 provides a legal framework for making decisions on behalf of a person who does not have the capacity to do so. It:

- covers the person's welfare, property, financial affairs and medical treatment
- enables people to make their own arrangements for how their affairs should be managed if they lose the capacity to make decisions in the future
- recognises that as far as possible, people should have autonomy and be able to control their own lives, and another person can only make decisions on their behalf when it is justified and necessary.

We will now examine how this piece of legislation may be applied when working with people with learning disabilities to promote equal health by working through a person's story. You will remember you were introduced to Sheila and Nan earlier in this resource.

Module 5

Human rights, learning disabilities and equal health

Sheila and Nan

Sheila is 50 and lives at home with her mother Nan, who is 75 and widowed. Sheila works in a café run by an organisation that supports people with learning disabilities. She is particularly fond of swimming and dancing, attends local clubs for both activities and has a wide range of friends through work and leisure activities.

Nan is 75. She was a Sunday school-teacher and remains an active member of her local church. She has a particular interest in art and occasionally paints watercolours as a hobby. Nan's sister, Claire, lives in London, but they remain in regular contact by phone. Claire tries to visit as often as possible and has always had a close relationship with Sheila.

Sheila has been identified as having a moderate learning disability. Nan's contribution to supporting Sheila is vital. It is she who ensures that Sheila carries out daily tasks such as managing her hygiene, dressing appropriately and preparing and eating food safely. Nan is keen to support Sheila to maintain links with the local community.

Shortly after her 50th birthday, Sheila received her first invitation for bowel screening. Nan supported Sheila to collect the samples required and the test results have now come back showing that blood has been found in her sample.

Sheila has been asked to attend an outpatient appointment for a colonoscopy, a further test for detecting bowel cancer. Because of Sheila's learning disability, issues are raised as to whether she can give informed consent for this procedure and what role Nan could play in giving consent on her behalf.

Important issues concerning medical treatment in Sheila's story are: capacity, consent, principles and legislation.

Learning activity

How would you define 'capacity'?

Record your answer here.

You should have placed an emphasis on:

- the importance of understanding the nature of the decision
- the consequences of the decision and people being able to retain the information
- capacity not being an all-or-nothing concept – a person may not have capacity at a particular point in time or for a particular decision, but this does not mean that he or she will never have capacity to make any decisions
- incapacity can be inherited or acquired, temporary, fluctuating or permanent.

Remember

The starting point for assessing someone's capacity to make a particular decision is always the assumption that the person has capacity.

The burden of proof in legal proceedings will fall on the person who asserts that capacity is lacking. Most often, incapacity is recognised and appropriate protection is put in place. At other times, however, capacity may be questioned inappropriately because a person simply has difficulty understanding or communicating information. As you know from your previous learning in this resource, understanding and communication can be particular issues for people with learning disabilities.

Linking back to Sheila and Nan's story, Part 5 of the Adults with Incapacity (Scotland) Act 2000 addresses medical treatment and research. There are very specific requirements for the assessment of capacity when it relates to consent for medical treatment. Normally, an assessment under Part 5 of the Act should seek to determine whether the adult:

- is capable of making and communicating their choice
- understands the nature of what is being asked and why
- has memory abilities that allow the retention of information
- is aware of any alternatives
- has knowledge of the risks and benefits involved
- is aware that such information is of personal relevance to them
- is aware of their right to, and how to, refuse, as well as the consequences of refusal
- has ever expressed their wishes relevant to the issue when greater capacity existed
- is expressing views consistent with their previously preferred moral, cultural, family and experiential background
- is not under undue influence from a relative, carer or other third party declaring an interest in their care and treatment.

People have a fundamental legal, ethical and moral right to determine what happens to their own bodies, and healthcare professionals must respect that right to autonomy. People must, therefore, give informed consent to all forms of healthcare, whether personal care or major surgery.

Learning activity

What do you understand by the term 'informed consent'?

Record your answer here.

You should have emphasised that consent is a process rather than a one-off decision. It should be seen as the voluntary and continuing permission of a person to receive a particular treatment or procedure based on adequate knowledge and understanding of:

- its purpose
- its nature
- any likely effects
- any significant risks of treatment, including the likelihood of its success and outcomes
- consequences of either no treatment or an alternative treatment.

Steps in the process include discussion with the person, provision of verbal and written information and the explanation of risks and benefits. It is important to demonstrate that information on a defined procedure/intervention is presented and described in a manner that aids the person's understanding: it may, for example, need to be presented in simplified language or pictorial/graphic format, or in ways that will accommodate sensory impairments such as visual and hearing problems. This will aid in clarifying and informing capacity.

All the steps you take to establish consent should be formally documented. A person must be properly informed about the risks, benefits and consequences of any proposed treatment and of possible alternatives before signing a consent form.

Learning activity

Access your organisation's policy on consent and assess how it addresses the issues raised in Sheila's story.

Record your answers here.

Let’s reflect on Sheila and Nan’s story.

- While Sheila may have capacity to make everyday decisions, it may be determined that she cannot give consent to medical treatment. In this case, the safeguards and protections provided by Part 5 of the Adults with Incapacity (Scotland) Act 2000 would apply.
- The involvement of Nan as Sheila’s mother in assessment of capacity is a specific requirement of one of the principles of the Act (relatives and others with an interest in the welfare of the adult must be consulted).
- In relation to consent to treatment, there are a number of possibilities in addition to seeking consent from Sheila:
    - it may be that Sheila has previously been assessed as incapable and has a certificate of incapacity that includes a treatment plan which can be put in place when the person is likely to need multiple medical interventions
    - however, she would still need to be assessed by a medical practitioner who would issue a Section 47 certificate and, if agreed, this procedure could be added to the treatment plan.

If this is not the case, consent could be sought from an appointed proxy, who may be Nan or another person. The proxy may be a Welfare Attorney (appointed by a person when they still have capacity) or Guardian (appointed by the court when the person no longer has capacity) who could give consent. It is important to establish if a proxy has been appointed: you could contact the Public Guardian or local authority for confirmation and details of who this is if Nan does not have the information.

Remember

It is illegal for a relative or another person to give consent without these proxy powers.

The Mental Welfare Commission has produced some useful guidance, **Consent to Treatment**, which can be accessed on their website. You may also wish to access the **Think Capacity, Think Consent** learning resource available on the **NES** website.

Adult Support and Protection (Scotland) Act 2007

The Adult Support and Protection (Scotland) Act 2007 came into force in 2008 and aims to protect adults who are unable to protect themselves and are at risk of harm. The Act includes duties, powers and responsibilities, particularly for local authorities, who have a lead role in adult protection. It also places a duty on NHS boards, police forces and other public bodies to cooperate with all measures relating to adult protection.

We saw in earlier modules that people with learning disabilities may be at more risk of harm, but it is important to recognise that having a learning disability does not automatically mean someone is an ‘adult at risk’. To be an ‘adult at risk’, the person must meet the ‘three-point test’: if an adult meets only one or two elements of the three-point test, he or she cannot be considered an ‘adult at risk’.

The three-point test

The adult is:

1. unable to safeguard his or her own well-being, property, rights or other interests
2. at risk of harm
3. more vulnerable to being harmed because he or she is affected by disability, mental or physical ill health.

We will now consider how this piece of legislation may be applied when working with people with learning disabilities by examining another person's story. You were introduced to Molly earlier in this resource, and we developed her story in subsequent modules.

Molly

Molly is a 22-year-old woman who works part-time in a café and lives a fairly independent life. She lives in her own flat and likes to go out with her friends.

Molly had difficulties in her early life and spent time in residential child care and a series of foster homes. She was regularly bullied at school.

Over her life, she has had a lot of contact with various health and social services professionals and has been identified as having a mild learning disability.

Molly has had a number of relationships and is sexually active, but does not use regular contraception. Two years ago, she had a child who was removed at birth by a court order. Molly recently met a man and he has moved in with her.

Learning activity

Do you think Molly meets the 'three-point test'?

Record your answers here.

From the information we have about Molly, we cannot immediately determine if she meets the 'three-point test'. While she has been identified as having a learning disability, this does not automatically mean she is at risk. It is the whole of the person's circumstances that can combine to make them at risk of harm.

In Molly's example, it would be important to determine if she is unable to safeguard her well-being and, as a result, is placing herself at risk. Under this piece of legislation, to be 'unable' means lacking the skills, means or opportunity to do something.

Does Molly have the capacity to safeguard herself? If she does not, she would meet the 'three-point test'. If, however, she is **unwilling**, rather than **unable**, to safeguard herself, she would not meet the 'three-point test'.

Determining if a person is an 'adult at risk' is often highly complex and is unlikely to be part of your role. It is nevertheless important that if you suspect a person may be at risk, you report your concerns to your line manager, who would in turn report it to the local authority.

Harm and abuse

People with learning disabilities are similar to many other groups in society who may be at risk of harm from other people, including from those close to or working with them.

The forms of abuse you were introduced to in the DVD and which we discussed in Module 3 include:

- **physical abuse**, such as being hit or injured on purpose
- **financial or material abuse** – theft, or misuse of money, property or personal possessions
- **emotional abuse** – intimidation, threats, humiliation, verbal or psychological abuse
- **sexual abuse** – involvement in sexual activity that is unwanted or not understood
- **neglect**, which can range from people not being provided with basics (such as food, clothing, attention or care) to failure to provide appropriate access to health and social services
- **discrimination** – treating people negatively because of their learning disability
- **restrictive practices** in health and social services, which can compromise people's liberty and human rights
- **misuse of medication** – giving medication inappropriately, overdosing or withholding medication.

Let's return to Molly's unfolding story.

Molly

Molly has had several attendances at accident and emergency (A&E) with her new partner with unexplained injuries. Staff suspect that she may have been subject to domestic abuse.

Learning activity

What action should staff take?

Record your answers here.

In Molly's situation, this is very complicated. She has a right to be safe, and this is possibly being violated. It could be that her partner has physically abused her and that she is the victim of domestic abuse. In this instance, it is important to speak with Molly without her partner being present and support her to tell her story. It is also important that Molly is enabled to see that her partner is putting her at risk and that he could be prosecuted for his behaviour.

On the other hand, Molly's injuries may have been accidental and may signal that something is changing in relation to her health. In this instance, it would be important that she gets a full medical check, remembering all the things you have learned so far in relation to the health and well-being of people with learning disabilities and how in many instances this can be overlooked.

Remember

If you suspect someone is being harmed or you observe him or her being harmed, you have a duty to report it to your line manager.

The level of knowledge you will require in relation to the Adult Support and Protection (Scotland) Act 2007 will reflect your role, and you should be able to access training in your local area. Your role is likely to be about contributing information for assessment and investigation, and reporting suspected abuse.

Working with risk and risk enablement

Life is never risk-free. Risk is part of all our lives, but assumptions about the capacity of people with learning disabilities to make decisions and take risks can result in their quality of life being restricted and lead to health inequalities. We need to balance risk and autonomy with our duty of care when we are working with people with learning disabilities.

Remember

People with learning disabilities need to feel safe and secure and be as independent as possible to achieve equal health.

People with learning disabilities are individuals. The recommended best-practice approach to working with risk and people with learning disabilities is '**risk enablement**'.

Traditionally, approaches to risk management with people with learning disabilities focused on the **downside of risk**, such as the risk that an event will turn out worse than expected. Another approach, however, is to think about the **upside of risk** – this is essentially what risk enablement is about.

Negotiating risk is neither the elimination of any activity that might produce a downside, nor an acceptance of all activities without boundaries. It is a conversation about who the person is, and asks:

- how they stand to benefit from engaging in an activity in terms of promoting their health
- what the downside risks are for their health
- how the risks can be mitigated to an acceptable degree to promote equal health.

Most organisations have a risk-management and enablement policy, and it is important to familiarise yourself with it. Thereafter, you should ensure your practice always complies with the policy.

Module 5

Human rights, learning disabilities and equal health

Module summary

We have identified in this module that people with learning disabilities, their families and carers have the same rights as everyone else in society. We need to empower, enable and support them to exercise their rights.

We explored what rights are and our duty to ensure the dignity, civil and legal rights of people with learning disabilities are respected, and that they are given the level of assistance they want and need to participate in decisions that affect their well-being.

We also looked at how a FAIR approach to decision-making can be used to protect the rights of people with learning disabilities so they can maintain their health and well-being.

The issues of capacity and consent and how they apply to your role were examined, alongside the principles and provisions of some legislation aimed at protecting people's rights and choices. Finally, we looked at situations in which people with learning disabilities may be experiencing neglect, harm or abuse and how they should be protected.

You should now be able to:

1. understand a human rights-based approach
2. apply a FAIR approach to decision-making when considering how best to reduce the risk of health inequalities within a human rights context
3. understand the principles of capacity and consent and how they apply to your role to inform and develop your practice
4. understand the principles and provisions of legislation in place to protect people with learning disabilities, their families and carers' rights and choices, and how this should inform your practice
5. understand when people with learning disabilities may be experiencing neglect, harm or abuse and how they should be protected.

Reflective account

Write a reflective account taking into consideration your learning from Module 5.

Below is a suggested structure you may find helpful in writing your reflective account.

What happened?

Identify and describe a situation or incident in which you were supporting a person with learning disabilities to maintain his or her health. When recalling this situation, you may wish to consider the following:

- adult protection issues
- the range of legislation and policy that protects the rights of people with learning disability in Scotland, such as capacity and consent, and risk and risk enablement.

Describe what you did or how you responded.

Describe the outcome of your actions or response.

So what does this mean?

How did you feel about the outcome of the support that you provided at the time?

What do you feel about that now, in light of your learning from the module?

What did you do that went well?

Do you think your actions helped to improve quality of life for the person you were working with?

What might you now do differently?

Now what will you do in the future?

How will this affect the way you work with people with learning disabilities in the future?

Would you act differently, or would you be likely to do the same?

What further learning do you need to undertake to enhance your understanding of learning disability that will help you to support people to achieve equal health? You may want to record this using the **paper into practice** activity at the end of the module.

Paper into practice

From your learning in this module, answer the following.

- How does your work setting actively promote the rights of people with learning disabilities?
- How can you use the FAIR approach when making decisions in practice?
- List two changes you will make in practice to ensure you are using a human rights-based approach that enables the people you are working with to maintain their health and well-being.

Make notes of your responses here.

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