



Learning outcome 4:

Understand the basic principles and practice of advocacy, empowerment and active participation in relation to supporting individuals with learning disabilities and their families

The following learning outcome has **four** assessment criteria:

- 4.1 Explain the meaning of the term 'social inclusion'
- 4.2 Explain the meaning of the term 'advocacy'
- 4.3 Describe different types of advocacy
- 4.4 Describe ways to build empowerment and active participation into everyday support with individuals with learning disabilities

Introduction

This learning outcome starts out by explaining what is meant by 'social inclusion', including a list of activities that people with learning disabilities can be supported to do so that they are more socially included. The meaning of the term 'advocacy' is explained and its key principles identified, and the different types of advocacy are described. Finally the learning outcome describes ways to build empowerment and active participation into everyday support with individuals with learning disabilities.

4.1 Explain the meaning of the term 'social inclusion'

Social inclusion means taking steps to change the way things are done so that groups of people who have historically been excluded from society can start to take their place as respected and valued members of their community. People with learning disabilities are one of the most excluded groups in society, so have a lot to gain from social inclusion. This is how Andrew Lee, Director of People First (Self-Advocacy), explains it:

'I think of life as a person with learning difficulties as being taken to watch a football match where life is that football match and never being allowed to join in. People with learning difficulties have the same dreams, inspirations and aspirations as anyone else but we are held back from fully taking part in life. If you think of your most cherished moments in life, of the things that you still look back on and smile, it is probably something that people with learning difficulties would get held back from doing. At the root of the barriers they face is an idea that they are less good and less worthwhile than other people'. (Lee, 2008)

It is this idea, that they are 'less good and less worthwhile than other people', which keeps people with learning disabilities on the margins, excluded from society.

Key learning point

Negative ideas about people with learning disabilities keep them shut out and excluded from the flow of community life. People with learning disabilities want to be included, not excluded.

Quite simply, social inclusion for people with learning disabilities means being able to do the things that people without disabilities take for granted – doing the things other people do. It means being able to live the life they want. Here are some of the things that people with learning disabilities can be supported to do so that they are more socially included:

- ▶ access public services such as health and social care, benefits and housing advice
- ▶ identify and access local facilities where they can meet friends or meet new people, for example social clubs, local societies, pubs, youth clubs, cinemas, places of worship
- ▶ identify and access opportunities to find out about sex and sexuality and to meet potential partners, for example I-said, Outsiders or the Hidden Loves Network
- ▶ find out about opportunities for paid work, work placements or volunteering
- ▶ leisure activities, for example swimming, shopping, going for walks or attending adult education classes
- ▶ travel to go out and about in their local area more independently
- ▶ visit their families or have their families to visit
- ▶ phone, text or email their friends and family.

Being supported to do these kinds of activities is important for all people with learning disabilities, but it is especially important for individuals who encounter extra challenges because they belong to a minority group. Such individuals – and they may belong to more than one minority group, for example a black female with high support needs – can experience increased levels of social exclusion (sometimes referred to as double or multiple discrimination). Minority groups, sometimes referred to as seldom listened-to groups, include the following:

- ▶ people from minority ethnic and faith backgrounds
- ▶ people with profound and multiple learning disabilities
- ▶ people whose behaviour is described as challenging
- ▶ gypsy travellers
- ▶ women
- ▶ older people.

Thinking activity

What is multiple discrimination? Who might experience it? Why?

Action!

Turn to the assessment section and complete questions 33 and 34.

4.2 Explain the meaning of the term 'advocacy'

Advocacy is when a person (the advocate) speaks up for or acts on behalf of another person who has communication needs (the advocacy partner) so that the advocacy partner has more choice and control in their lives. Advocacy services are needed because mainstream public services can fail to provide adequate support to the most vulnerable members of society, including people with learning disabilities.

Thinking activity

What do you think it might feel like to not be able to stand up for yourself? What might it feel like to have to depend on someone else to protect and promote your interests?

If an individual has communication difficulties, difficulties understanding or severe learning disabilities, they may not be able to work with an advocate or tell them what they want. Such individuals can be supported to use non-instructed advocacy, which seeks to ensure that they are enabled as far as possible to live in the way they choose. Non-instructed advocacy is geared towards the needs of those who are most vulnerable and least able to be a part of decisions made about them.

There are different types of advocacy (see assessment criterion 4.3 Describe different types of advocacy) but they can all support people with learning disabilities to:

- ▶ be clear about their needs and preferences
- ▶ express their needs and preferences effectively
- ▶ get independent advice and accurate information
- ▶ negotiate and resolve conflict
- ▶ take control of their lives.

For example, imagine a young couple with learning disabilities have a baby and start to find it difficult to cope. The initial response of social services might be to permanently remove the baby from the care of its parents, without adequate effort being made to support the parents to carry on caring for their child, as the law requires. However, the involvement of an advocate can enable the parents to identify and access the parenting and domestic support they need in order to ensure the baby's continued health and safety. In this way, the parents are able to carry on caring for their baby and so keep their family intact.

Key learning point

Advocacy is like a bridge, enabling individuals to overcome the barriers they face and gain access to the services they are entitled to.

The key principles of advocacy are as follows:

- ▶ what the individual says and wants is the most important thing, regardless of whether or not the advocate agrees
- ▶ full inclusion of individuals as contributing and participating members of the community
- ▶ no conflict of interest – the advocate must be independent of the service provider so they can speak up for the individual effectively
- ▶ the individual must have a choice about the type of advocacy they use.

Action!

Turn to the assessment section and complete questions 35 and 36.

4.3 Describe different types of advocacy

Different types of advocacy exist to suit different types of individual and different types of need. An individual may need or prefer different types of advocacy at different stages in their life, or at different stages in a negotiation process. Some individuals prefer a one-to-one relationship and so opt for the services of an independent advocate, while others may value shared experience and choose peer advocacy (see

below). People with learning disabilities find out about advocacy via awareness-raising sessions in their residential care home or day centre, or they may know someone who has used or provided advocacy.

Key learning point

Different individuals prefer different types of advocacy. All types of advocacy put the individual's interests and needs first and foremost.

Self-advocacy

This is speaking up for yourself and it is what most people without disabilities do most of the time. People with learning disabilities may need support to speak up for themselves and may also find it difficult getting others to listen. Self-advocacy groups are run by and for people with learning disabilities, sometimes with people to support them. Often these groups use the same services or have shared interests and individuals and find that being part of the group helps them to have a say in how those services are run. In addition, belonging to a self-advocacy group can have a positive effect on individuals' confidence and independence, allowing them to share problems, make choices and take more control over their lives. According to People First, a national network of self-advocacy groups, 'people's whole lives change through self-advocacy' (People First, 2011).

Citizen advocacy

If a person with learning disabilities is at risk of having their choices, wishes or needs ignored, they may need support to make sure things happen the way they want them to. A citizen advocate can speak up for the individual in such circumstances. A citizen advocate is someone who volunteers to support and speak up for their advocacy partner. The partnership is long-term and not time limited and lasts for as long as both partners want it to.

Peer advocacy

This is when the advocate and advocacy partner share similar experiences or a similar environment. The strength of this type of advocacy is that the advocate can be more effective in promoting the individual's needs and wishes because of their shared experience. Peer advocacy is often supported by self-advocacy groups or by a citizen advocate.

Case advocacy

Case advocacy is similar to citizen advocacy but focuses on a specific issue or set of circumstances and so is not intended to be a long-term arrangement. It may be provided alongside citizen, peer or self-advocacy in order to address a particular problem – if, for example, there has been a breakdown in the advocacy relationship or because some kind of special expertise is required.

Independent advocacy

The role of the independent advocate is a combination of citizen and case advocacy, with the difference that an independent advocate typically works for an advocacy organisation and is a paid employee. An independent advocate typically has a caseload of several clients and, once the issue has been resolved, the advocacy relationship normally comes to an end. As the name implies, an independent advocate is wholly independent from service providers so as to avoid any conflict of interest.

Thinking activity

If an advocate started working with an individual you supported, how would you respond? Do you think there might be difficulties to overcome in the relationship between an individual's advocate and their support worker?

Action!

Turn to the assessment section and complete questions 37–39.

4.4 Describe ways to build empowerment and active participation into everyday support with individuals with learning disabilities

For individuals with learning disabilities, empowerment and active participation come from having choice and control over the care and support they receive. As you have seen in learning outcome one, the personalisation agenda seeks to maximise choice and control for individuals who use social care services. It does this by using person-centred planning to design and provide services. Person-centred planning 'shifts power from professionals to people who use services' (DoH, 2010, p 3) and is based on a range of practical, person-centred thinking tools. As Mencap states, '...person-centred approaches are a core element of all good practice and should be integral in all delivery of care and support' (Mencap, 2011b).

Building empowerment into everyday support

Empowerment is about supporting and developing the individual's confidence in their abilities so that they can, over time and to the greatest extent possible, take control over their own support services. Empowerment means identifying the things that the individual can do and supporting them with the things they find challenging. It uses this information to support the individual to contribute, however large or small the contribution, so they begin to take more control over their care and support. Working

in this way can help to improve the individual's confidence in their abilities and thereby motivate them to achieve more.

An important part of building empowerment is the way you assess and manage the risks involved in an activity. Individuals may find their choices and independence restricted by service providers because of a perceived risk. In order to build empowerment into the support you provide, you need to assess any risks against the likely benefit to the individual of taking part in the activity in question. Building empowerment into support means assessing and managing risk in such a way as to maximise the individual's independence and choice, while at the same time ensuring their safety and the safety of those around them. Remember, any decision about risk needs to be jointly made between you and the individual.

There are a range of 'tools' to use in person-centred thinking that provide models for identifying the things an individual can do and the things they find challenging. These tools help focus on:

- ▶ the individual
- ▶ their gifts and skills
- ▶ what is important to them
- ▶ how best to support them.

Person-centred thinking tools can bring immediate and lasting changes to individuals' lives and to the way professionals and support staff operate.

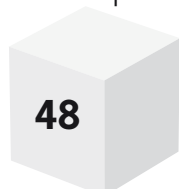
Graham uses a wheelchair, has profound learning disabilities and doesn't communicate verbally. For years, the most significant part of his life was attending a day service where there was an over-reliance on repetitive activities like jigsaws. By using person-centred thinking tools to work out Graham's abilities and what was important to him, staff members realised he suited office work. He consequently attended a job centre interview and now works at the Derbyshire Centre for Integrated Living. He has thrived there, is happier, more engaged and more communicative. Using person-centred thinking made that happen. (DoH, 2010, p 14)

For this individual, person-centred thinking tools have brought about a radical transformation of his day-to-day experience. A summary of some of these tools and how they can be used is on the next page.

Person-centred thinking tool	What it does	How it can help
Sorting 'important to' from 'important for'	Sorts what's important TO an individual (what makes them happy, content, fulfilled) from what's important FOR them (health and safety, being valued), while working towards a good balance	<ul style="list-style-type: none"> ▶ As a way to think through a situation before deciding what should happen next ▶ As an everyday tool ▶ As the beginning of a person-centred plan
Relationship circle	Identifies who is important to an individual or family	<ul style="list-style-type: none"> ▶ Learn who is important to people ▶ Identify relationships that can be strengthened or supported
Communication charts	Helps to focus on the individual's communication, whether they use words or not. To be used whenever an individual's action communicates a message more clearly than their words	<ul style="list-style-type: none"> ▶ A quick snapshot of how someone communicates ▶ A way of enriching the information available about people who use words to speak but especially about those who don't
Learning log	Directs people to look for ongoing learning. A structure that captures details of learning within specific activities and experiences. A way of recording what needs to stay the same and what needs to be different about how an individual is supported	<ul style="list-style-type: none"> ▶ Can replace traditional notes or records to help focus more clearly on critical information about the individual ▶ Can be used to focus on someone's whole life or on specific areas of their life, eg. someone's health, or how they like to spend their time
Sorting 'what's working' from 'what's not working'	Clarifies what to maintain or enhance and what to change. Helps in looking at how any part of a person's life is working – are medications working? Are people providing paid support doing their work? Is a particular effort, activity or project working? Helps with mediation when there are disagreements	<ul style="list-style-type: none"> ▶ Analyses an issue or situation from different perspectives ▶ Provides a snapshot of how things are right now

(Adapted from DoH, 2010, p 16)

By using these person-centred thinking tools, you can begin to form the foundation for a person-centred partnership with the individual you are supporting.



Key learning point

Person-centred approaches are the foundation of all good practice. They should underpin everything you do.

Building active participation into everyday support

Active participation is at the heart of providing person-centred support. It is a way of working that recognises an individual's right to participate in the activities and relationships of everyday life as independently as possible; the individual is regarded as an active partner in their own care or support, rather than as a passive recipient (Skills for Care, 2010, p 13).

There are four main components involved in building active participation:

- ▶ valuing individuals for who they are
- ▶ enabling individuals to make informed choices about their lives
- ▶ knowing about practical ways to support active participation
- ▶ enabling individuals to access support networks and participate in the planning, development and evaluation of services.

Valuing individuals for who they are

People with learning disabilities are individuals, like anyone else. Each has their own, unique life story that has brought them to the present moment. Each individual with learning disabilities has the same human rights as anyone else, and the same right to pursue their dreams and aspirations. As a learning disabilities support worker, it is important that you respect each person you work with as an individual and that you recognise their right to live a full life as a valued member of their community. Achieving this consistently within the constraints of a busy working day can be a challenge. So it is important that you cultivate and maintain positive attitudes and behaviours as you go about your work. This will improve the support you are able to provide and may also make your working day more enjoyable and rewarding. Positive attitudes and behaviours include:

- ▶ showing interest in the individual you are supporting – interest in what they have to say, their opinions and beliefs
- ▶ being non-judgemental
- ▶ being polite and respectful as you go about your work
- ▶ always maintaining your professional boundaries
- ▶ not letting it show if you are in a bad mood or if things are not going well for you that day
- ▶ being open to new ideas the individual comes up with and enthusiastic about trying them out

- ▶ always being optimistic, especially when there are setbacks or difficult challenges to deal with.

In order to be able to provide this level and quality of support, you need to get to know the individual you are supporting, finding out about their family and loved ones, their interests, hobbies, values and preferences, their past experiences. Getting to know the people you support is especially important if they have extra communication needs or if they have a different cultural background to yours. For example, if you are supporting an individual from a Jewish or Hindu background, you may need to make sure you know about the religious and cultural practices that the individual may want to follow. Or if you are supporting a young person with learning disabilities, you may need to get up to speed with popular music, sport or current events. You won't know what inspires and fires people until you get to know them as individuals.

Thinking activity

If you were asked to support an individual from a Muslim background, what cultural beliefs and practices might you need to find out about? Do all Muslims share a common cultural background?

Enabling individuals to make informed choices about their lives

Individuals cannot actively participate if they do not know what their options and choices are. This aspect of promoting active participation is primarily to do with ensuring that the individuals you support have ready access to accurate advice and information in order to make good decisions. For example, the individual you are supporting may wish to join a support network for people with learning disabilities to be able to share experiences and perhaps lobby for change. Or they may wish to find out about restaurants with wheelchair access or cinemas that have parent and toddler showings. Whatever the change or choice the individual wants to make, it is up to you to provide the appropriate information, in an accessible format, to enable them to make the choice that is right for them.

By making informed decisions, individuals can be supported to feel confident and in control of their lives, and their relationship with you will be made stronger. The more trust there is between you and the individual you are supporting, the better and more individualised the support you are able to provide. Enabling individuals to make informed choices about their lives is essential in building active participation into everyday support.

Practical ways to support active participation

Here, your role is to make sure that the individual you are supporting has everything they need to take part as fully as they can in the activities and relationships of everyday life. Again, in order to do this, you will need to support the individual to make good choices by identifying and making available to them accurate, relevant advice and information. For individuals with learning disabilities, many of whom have additional

communication needs, this may involve supporting the individual to communicate to their full potential by enabling access to appropriate communication aids and resources. These may include low tech communication aids such as signs, symbols, pictures or objects of reference, as well as high tech aids, ranging from simple battery-powered button communicators (where single requests or messages are triggered by pressing colour-coded buttons on a panel) to relatively sophisticated speech-generating devices.

In addition, there is now a range of assistive technologies to support people to remain safe, independent and in control in their own homes. To build active participation into everyday support, you must ensure you are aware of the range of assistive technologies available and discuss them with the individuals you support regularly, accessing information and supporting individuals to use equipment so they can gain in independence and confidence.

Two types of equipment are available:

- ▶ daily living aids
- ▶ telecare.

Daily living aids

These can help to put individuals in control of their activities and support them to rely less on others. Examples include:

- ▶ tap rails and bath seats to make it easier to get in and out of the bath
- ▶ shower mats and temperature measures to reduce risk of accidents and help individuals to feel more confident to bathe independently
- ▶ button fasteners and zip clips to support dressing independently
- ▶ kettle tippers to hold a kettle in place – with a simple touch the kettle will tip and pour water into a mug
- ▶ 'caring cutlery' to enable individuals to get a better grip of their knife and fork when eating
- ▶ non-slip mats to keep plates of food secure while individuals are eating
- ▶ vegetable cutting devices to make preparing food easier
- ▶ tap levers to make it easier to turn water on and off around the home
- ▶ swivel seats to support movement when transferring, for example from a wheelchair to a chair.

Telecare

Telecare is a service which uses a range of technology-based equipment to monitor an individual's home to help keep them safe and secure. Telecare equipment uses generally small and unobtrusive devices that blend in to the home. The devices provide reminders and prompts for things like when to take medication, and can automatically call for assistance in emergency situations, for instance if the individual has a fall or if

there's a fire. Telecare can make individuals feel safer and more secure in their homes and so promotes confidence and greater independence. It enables individuals to take more responsibility for themselves and rely less on others. Examples include:

- ▶ bed occupancy sensors
- ▶ epilepsy sensors
- ▶ gas shut-off devices
- ▶ emergency pendants
- ▶ movement detectors
- ▶ medication reminders.

Enabling individuals to access support networks and participate in the planning, development and evaluation of services

For an individual to be an active partner in their own care and support, you will need to advise them how to access support networks and participate in the planning, development and evaluation of the services they use. You will need to access or facilitate access to a range of information sources, many of which will be charities, voluntary organisations or user-led organisations working at a local, regional or national level. Such organisations can provide accessible information, access to support networks in the local area and opportunities to become actively involved in service planning, development and delivery.

They can be found on the internet and your local library will have a directory of local services and organisations with a description of what they do as well as their contact details. Examples of such organisations, many of which operate nationally but also have local affiliated groups, include:

- ▶ Learning Disability Alliance Scotland (www.ldascotland.org)
- ▶ Disability Wales (www.disabilitywales.org)
- ▶ Mencap (www.mencap.org.uk)
- ▶ British Institute of Learning Disabilities (www.bild.org.uk)
- ▶ Electronic Quality Information for the Public (www.equip.nhs.uk)
- ▶ People First (www.peoplefirstltd.com)
- ▶ National Autistic Society (www.nas.org.uk).

In addition, there are a number of local and regional organisations that specifically seek the input and involvement of people with learning disabilities. In England, these include:

- ▶ Learning Disability Partnership Boards (county level) (www.valuingpeoplenow.dh.gov.uk/find-your-partnership-board)

- ▶ Valuing People Local Implementation Groups (local)
(see for example www.pcp-in-hampshire.org.uk/documents/post316.pdf).

By joining such groups, individuals can get involved in preparing job descriptions for workers, recruiting new staff and planning changes to services. In addition, they can look at current services and how they can be improved and also comment on the provision and availability of services.

Action!

Turn to the assessment section and complete questions 40–50.



Learning outcome 5:

Understand how views and attitudes impact on the lives of individuals with learning disabilities and their family carers

This learning outcome has **four** assessment criteria:

- 5.1 Explain how attitudes are changing in relation to individuals with learning disabilities
- 5.2 Give examples of positive and negative aspects of being labelled as having a learning disability
- 5.3 Describe steps that can be taken to promote positive attitudes towards individuals with learning disabilities and their family carers
- 5.4 Explain the roles of external agencies and others in changing attitudes, policy and practice

Introduction

This learning outcome begins by explaining how attitudes are changing towards individuals with learning disabilities, then goes on to give examples of the positive and negative aspects of being labelled as having a learning disability. Steps are described that can be taken to promote positive attitudes towards individuals with learning disabilities and their family carers. In the final section, the roles of external agencies and others in changing attitudes, policy and practice are explained.