

Making services accessible to people with learning disabilities – including family carers



Learning disabilities and family carers project 'How-to' guide 2

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1. This Guide

This guide is the second in a series of three 'How-to' guides for Crossroads Care providers and The Princess Royal Trust for Carers' Centres supporting family carers of people with learning disabilities as well as, increasingly, giving people with learning disabilities a break from their caring role.

Many people with a learning disability live at home with parents or other family carers who are getting older and who need increasing support and care themselves. Others leave home to marry or live with a partner or friend who might need extra help and support because of their disability. Their needs might be very different from someone with a learning disability who is cared for by their family. The important thing is to think carefully about the best way to plan activities for everyone you support.

Services with links to carers' groups or workers might look for ways for these to support carers with a learning disability or mutual carers. They might be unaware of this group of carers. People with a learning disability might need support to attend meetings or might prefer a separate carers group to meet their particular needs.

2.Planning group and individual activities

People with learning disabilities have not always had much control over their lives. They have often been offered limited choices with little input into decisions made on their behalf. The Valuing People¹ white paper in 2001 challenged the impact this could have and promoted person-centred planning as an approach to improve the lives of people with learning disabilities. Valuing People Now² was published in 2009 to refresh and re-state these aims.

The aim of person-centred planning is to empower people with learning disabilities to live as independently as possible and to be part of the 'mainstream', rather than reliant on specialist support.

Person centred planning means listening to people to find out what is most important to them and what they want from their lives. However, it is not just about producing plans – the focus must be on making things happen. Planning is a long-term process that involves those who know the person well and this is clearly going to be difficult to implement if you are only supporting someone for a few hours or days to give them or their carers a break. However, the principles of person-centred planning and an understanding of person-centred approaches to planning should underpin the activities that you offer. In its simplest form, this would mean:

- Listening to and learning from the person
- Taking into account their needs, interests and concerns
- Involving others within their personal networks
- Tailoring the activity to the person, rather than assuming they will fit in with existing activities
- Thinking about the support they might need to do the things that are important to them

Some negotiation and compromise may have to be made when people are sharing resources or activities, but taking a person-centred approach should help you think creatively about meeting different needs.

3.Listening to the person

'Listening' will probably be far more complex than simply asking the person what they want to do. It could involve observation, talking to other people or giving the

¹ The Department of Health (2001); *Valuing People: A New Strategy for Learning Disability for the 21st Century*.

² The Department of Health (2009); *Valuing People Now: a new three-year strategy for people with learning disabilities*.

person the opportunity to try new things and recording how they respond to them. If they have a person-centred plan, this might identify things that you could support them to do. This applies particularly to supporting people with a learning disability and complex needs.

A good starting point is to look at things from the person's perspective and think about:

- What a good day is like and how they indicate they are happy
- What a bad day is like and how they indicate they are unhappy
- What makes them happy
- What makes them sad or upset
- What are their important routines
- What people or places are important to them.

4. Learning from the person

Learning from the person involves using what you find out and sharing this with others. This is particularly important where people have no formal communication or very complex needs that mean they depend on others to interpret what they want or feel.

If you discover that someone really enjoys bowling but prefers to go during the day when things are quiet, this needs to be recorded and shared. If someone else takes them to a loud and busy evening session, this will be a completely different activity that they might dislike. There is a risk that people will decide not to take them bowling again.

Recording activities can be as simple as giving people a disposable camera to record their activities or using digital or video cameras to capture what they are doing. Talking photo albums (available from suppliers like www.inclusive.co.uk, Amazon or www.talkingproducts.co.uk) give people the opportunity to record a comment (or for someone to do this for them) next to each photograph. Inexpensive pocket photo albums are ideal for keeping not just photographs but other things to remind people of an activity such as cinema tickets, programmes or train tickets.

Planning what to do can be an activity in its own right, for example:

- Working on a photo album, scrapbook or poster of things the person has done or would like to do
- Using storytelling to explore important people, places or things
- Collecting information from the leisure centre, tourist information centre or internet.

A group activity where everyone says one thing they would like to do and the group try to plan a day that would include elements of all these things. The focus should not just be on the activity but on everything that contributes to that activity. For example:

- Time of day
- Location
- Support – level and who gives that support
- Transport
- Different aspects of the activity.

Using horse riding as an example - someone might like the experience of travelling to the stables with other people and enjoy playing with the dogs or helping to clear the straw out of the stables, but then indicate that they do not want to ride a horse. By breaking the activity down into its various parts it is possible for the person to have a say in what they do and to support people with different interests within the same activity.

Taking this person-centred approach will mean that people with a learning disability are more actively involved in planning activities, recording how things went and deciding what else they would like to do and the support they need to do this. This is particularly important where people need additional support because of their behaviour, communication needs or autistic spectrum conditions. Getting all the right elements in place for an activity can mean the difference between a very positive or negative experience.

5. Support planning

For most people, the break will be identified in their support plan as a need for them or for their carers. You will need to make links between what the person wants to do and their support plan and identify:

- Who is responsible
- What they have agreed to do
- When they will do it
- Who will make sure things go to plan
- Names and contact details of key people.

This will be reviewed regularly to make sure the person is getting the support and opportunities they need.

6. Cultural competence

Cultural competence means delivering services or support to individual people in ways that are most appropriate for them and that address inequalities to give them the best possible support.

There are reasons why some groups of carers are much less likely to access services or support and these are discussed in the third of these guides.

A person-centred approach means looking at a person's culture from *their* perspective, rather than making assumptions about what it might mean to them. Someone who worships regularly with their family might want support to continue to do this. On the other hand, they might see a break as an opportunity to do something completely different. It is useful to understand the different traditions and beliefs that might impact on a person's life but then take time to understand what these mean for each individual.

7. Accessible information

Making breaks accessible and appropriate will also include making sure information is available in a range of formats to meet individual needs. Making services accessible for people with a learning disability can also mean that others, including people from Black and Minority Ethnic communities find information or communication easier to understand.

There is no 'one size fits all' solution but the key points to remember are:

- Be clear about who will be using the information
- If possible, involve people who will be using the information in producing it
- Use everyday language with no jargon – write as you would speak
- Keep to just one idea in each sentence
- Use a large, clear typeface and simple punctuation
- Use numerals not words to express numbers
- Use bullet points or boxes to highlight the main ideas
- Use symbols, drawings or photos to explain the words. For most people representations of real objects or people work best, but you will need to check this with each person individually. Make sure you do not introduce a whole new 'vocabulary' of symbols or pictures to someone. Use what they are familiar and confident with. A very quick and easy solution is to leave spaces next to the words in a document then print pictures or symbols onto large parcel labels. These can be stuck on to personalise the document with images that have meaning to the person.

Other formats like video or audio do not need to be too 'high tech'. Flip video cameras (www.theflip.com) are about the size of a mobile phone, have a simple button control and download images simply via the USB fitting that flips out of the camera.

Powerpoint presentations provide the opportunity to run a sequence of photos or words and add sound effects, speech or music. If you click the 'help' button on a blank presentation it will guide you through most of these basic tasks. Clear for All have lots of information about making information accessible, including step by step instructions to do things like add sound to a Word document (www.clearforall.co.uk/free_stuff.htm). They are also compiling a list of clear explanations for different words.

Other suggestions for things to consider when producing information for people with a learning disability are available from:

- Change - *How to Make Information Accessible - A guide to producing easy read documents*. Available from www.changepeople.co.uk
- Inspired Services - *How to produce information in a more accessible way* Available from www.inspiredservices.org.uk/freelogin.html
- Mencap – *Making It Clear*. Available from www.mencap.org.uk
- RNIB – *Making Your Information Accessible*. Available from www.rnib.org.uk

8. References and contact details

The Department of Health (2001); *Valuing People: A New Strategy for Learning Disability for the 21st Century*. Various documents are available at <http://tinyurl.com/vpnow>

The Department of Health (2009); *Valuing People Now: a new three-year strategy for people with learning disabilities*. <http://tinyurl.com/valpeople>

Further information can be found on The Princess Royal Trust for Carers' three websites www.carers.org, www.carers.org/professionals and www.youngcarers.net, and on Crossroads Care's website, www.crossroads.org.uk, or by contacting Cath Baker, Policy and Development Officer (Learning Disabilities), telephone 01568 760027, email cbaker@carers.org.

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