

How to...

Make reasonable adjustments to diabetes care for adults with a learning disability

Use this guide to:

- Deliver diabetes care that is accessible to adults with a learning disability
- Assess an existing service for its accessibility.

This guide is for:

- Healthcare professionals
- Service managers
- Quality improvement leads
- Network leads
- Health service commissioners.



What is a learning disability?

A learning disability is a reduced intellectual ability and difficulty with everyday activities – for example household tasks, socialising or managing money – which affects someone for their whole life.

People with a learning disability tend to take longer to learn and may need support to develop new skills, understand complicated information and interact with other people.

The level of support someone needs depends on the individual. For example, someone with a mild learning disability may only need support with things like getting a job. However, someone with a severe or profound learning disability may need fulltime care and support with every aspect of their life – they may also have physical disabilities.

People with certain specific conditions can have a learning disability too. For example, people with Down's syndrome and some people with autism have a learning disability.¹

Under the Equality Act 2010 health services are required to adjust their care to take account of these factors.

What are reasonable adjustments?

Reasonable adjustments are changes or additions to existing services designed to make them more accessible and effective for disabled people. Their aim is to ensure that disabled people are not excluded from services, and can achieve the same outcomes as those who are not disabled.

There are **three things** to consider when making reasonable adjustments:

- 1 Does the diabetes service have all the components it needs** to ensure accessibility to and effectiveness for people with a learning disability?
- 2 Are there systems in place** to ensure individuals are assessed and the appropriate adjustments are made to meet their personal needs?
- 3 Do the people in the service have the right knowledge and skills?**

This guide sets out **five steps** to help your diabetes service meet the needs of people with a learning disability. You can evaluate your service by using the assessment checklist at the end of **step 5**.

¹ More information available at www.mencap.org.uk/learning-disability-explained/what-learning-disability

Step 1 Make information accessible



All organisations that provide NHS or social care must follow the **Accessible Information Standard by law:** www.england.nhs.uk/ourwork/accessibleinfo

Accessible materials, sometimes called ‘easy read’, use language that is easy to understand, reinforced by images and graphics. Some services may need to commission locally-specific materials.

You can create a library of accessible materials that covers the following:

How to access and use services

- Letters offering an appointment or explaining a referral
- Explanations about how to contact a service and make an appointment
- Information about how to get there – including help with transport/mobility problems.

Explaining diabetes and the importance of diabetes treatment

- What diabetes is and how it affects your body – in terms that are easy to understand
- Having a blood test and home blood glucose testing
- Taking medication – reason for taking and importance of adherence
- Injections or insulin pump
- Looking after feet and eyes – and why this is important
- Risk of complications and how to prevent
- Hypos – what they are and what to do about them
- Importance of attending appointments and annual review.

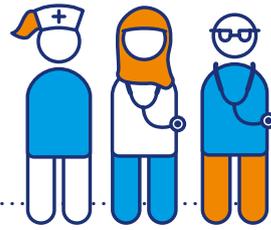
Explaining the need to change and how to make changes

- Reasons to lose weight
- Healthy eating and making healthy food choices
- How to lose weight
- Simple steps to increase activity and managing daily life
- Managing Type 1 and 2 diabetes.

Making weight loss and self-management materials accessible

- Helping with goal setting and getting support from healthcare professionals
- Monitoring progress and feedback
- Involving supporters and caregivers.

Step 2 Provide training for staff



Everyone can and should learn how to make reasonable adjustments but some basic training can improve confidence and communication skills. Ask your local learning disability service for help training staff to understand and respect the needs of people with a learning disability.

Consider covering the following areas during any training:

For all staff

- What is a learning disability
- Health needs of people with a learning disability – physical and mental health
- The Equality Act 2010 and requirement for reasonable adjustments
- What is meant by ‘reasonable adjustments’
- Communicating effectively with people with a learning disability, for example during face-to-face contact, by telephone, in writing. For more information visit the Diabetes UK resource library www.diabetes.org.uk/learning-disability
- Assessing mental capacity and gaining consent (Mental Capacity Act 2005)
- Person centred care for people with a learning disability
- The importance of working with caregivers and supporters.

For staff supporting behaviour change

- Helping with setting straightforward, clearly defined goals
- Monitoring progress and feedback
- The role of family and friends and other people who help
- Liaison between physical and mental health services.

Step 3 Address social barriers

Practical barriers

Health services may not have a responsibility to provide all types of support, but they need to know where this support is available. For example:

- Providing or funding transport for those with travel difficulties to health appointments
- Providing access for people with mobility problems
- Availability of communication aids
- Provision of support or advocacy for people with a learning disability
- Financial support for out of pocket expenses.

Other people: lack of understanding

People with a learning disability want staff to speak in a way they can understand. This can mean slowing down, using easy to understand words, listening, checking for understanding and trying different ways to communicate. People with a learning disability would like staff to speak to them as well as their supporter. For more information visit the Diabetes UK resource library

www.diabetes.org.uk/learning-disability

Involving people with a learning disability in training is valuable in helping staff to understand their experience of healthcare. Check for training in your local area.

Diagnostic overshadowing

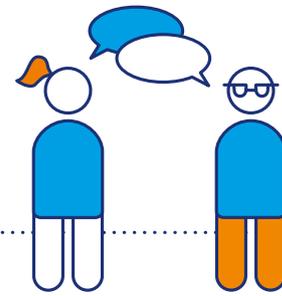
Diagnostic overshadowing is when professionals see the disability first, rather than the health problem. Careful listening is essential to avoid misattributing symptoms of physical or mental ill health to the learning disability. For example, a change in behaviour which is new can sometimes be a sign of pain or mental health difficulties.

Identifying people with a learning disability

All people with a learning disability can join the learning disability register at their GP Practice. This has the advantage that it flags a need for reasonable adjustments. Research shows that lots of people with a milder learning disability miss out on being on the register.

Even if the person does not qualify for an annual Health Check everyone with a learning disability is entitled by law to reasonable adjustments to their care. Practice notes (including electronic records) should record all patients with a learning disability and the reasonable adjustments that person requires, so this information is shared by staff.

Step 4 Involve supporters



Always check with the person with a learning disability – do they want a supporter involved in their healthcare? And, if so, who?

Here are six questions to help you identify key supporters and helpers where it isn't already clear.

Ask the person with the learning disability:

- Who do you live with?
- Who helps with your shopping?
- Who cooks your meals?
- Where do you eat, and who with? (home, work, clubs/day centres)
- Do you go to any clubs or day centres? Who do you meet there who helps you?
- Do you go walking, swimming or do any other activities – who with?

Services should ensure supporters are actively involved with care – with consent if the person with a learning disability has mental capacity. Here are some ways to involve supporters:

- Always invite them to appointments
- Arrange appointment times that the supporter can attend
- Include the supporter in the conversation with the person with a learning disability
- Ask their opinion about what would help
- Negotiate some joint tasks to involve them in care
- Provide materials for the supporter to read with the person they support at home
- Check what support the supporter needs – and offer advice about what help is available for supporters. Remember that the main supporter of a person may also have a learning disability.

Step 5 Plan for and make reasonable adjustments



People with a learning disability will have differing needs, so reasonable adjustments need to be tailored to the individual.

Work with the person with a learning disability (and their supporter if needed) to identify, plan for, make and review the right adjustments for them.

Here is a list of some common needs and adjustments that can be made:

Example	Possible adjustments you can make
Needs help understanding letters or written information	Easy read letters; identify preferred means of communication and who to contact. Phone calls to help make appointments especially if the person has a visual impairment
Needs help understanding diabetes and how to change lifestyle	Easy read materials with simple verbal explanations. Check understanding. Briefing materials for supporters. Longer appointment times
Needs support to remember instructions or appointments	Reminders and phone calls. Easy read instructions. Involve caregivers and supporters
Physical or sensory disabilities	Practical aids that can be used by the individual
Feels depressed and neglects self-care	Mental health/liaison arrangements with learning disability services
Finds crowded spaces or waiting distressing	Appointment at beginning or end of clinic session. Mental health/liaison arrangements Home visits
Finds change to routine very challenging	Staff training and access to advice from specialist learning disability services
Needs help explaining symptoms, or side effects of medication	Involve a supporter who knows the person. Easy read information about possible side effects
Has difficulty using public transport	Home visits. Supported travel

Evaluating a diabetes service: a checklist

Use this checklist to help you evaluate how well a service is doing in making reasonable adjustments.

It's also important to get feedback from people with a learning disability and their supporters to find out what they think about the service and what could be improved.

1 Accessible (easy read) materials

How to access and use services	Check
Simple letters offering an appointment or explaining a referral	
Explanations about how to contact a service and make an appointment	
Importance of attending appointments and annual review	
Advice about how to get there – including help available with transport/mobility problems	
What diabetes is in simple terms and how it affects the body	
Having a blood test and home blood glucose checking	
Taking medication and the importance of adherence	
Injections and insulin pump	
Looking after feet, skin and eyes – and why this is important	
Hypoglycaemic episodes – what they are and what to do about them	
Risk of complications and how to prevent	

Explaining the need to change and how to make changes	Check
Reasons to lose weight	
Healthy eating – what that means and making healthy food choices	
How to lose weight	
Simple steps to increase activity	
Managing Type 2 diabetes	
Managing Type 1 diabetes	

Supporting behaviour change	Check
Helping with goal setting and getting support from healthcare professionals	
Monitoring progress and feedback	
The important role of supporters in making change happen	

2 Staff training

Is there documented evidence of staff training in the following areas	Check
For all staff	
What is a learning disability	
Health needs of people with a learning disability – physical and mental health	
The Equality Act 2010 and requirement for reasonable adjustments	
The Accessible Information Standard	
What is meant by ‘reasonable adjustments’	
Communicating effectively with people with a learning disability	
Mental Capacity Act, assessing mental capacity and gaining consent	
The importance of working with caregivers and supporters	
For staff supporting behaviour change	
Helping with goal setting	
Monitoring progress and feedback	
The important role of supporters in making change happen	

3 Practical support for accessibility

Is there documented evidence of	Check
Providing or funding transport for those with travel difficulties	
Providing access for people with mobility problems	
Availability of communication aids	
Availability of longer appointments	
Provision of support or advocacy for people with a learning disability	
Financial support for out of pocket expenses	
Communicating effectively with people with a learning disability	

4 Monitoring services

Is there evidence that the service is monitoring and reporting on its use by people with a learning disability	Check
Monitoring service use	
Recording of initial contacts made for adults with learning disabilities	
Recording of involvement of supporters	
Recording of follow up contacts made (number of visits or contacts)	
Recording of materials provided	
Monitoring of referrals to relevant services	
Structured education for Type 2 diabetes	
Lifestyle weight-management	
Bariatric surgery	

Useful reading

For professionals

Diabetes UK

www.diabetes.org.uk/learning-disability

NHS Right Care Pathway for Diabetes

www.england.nhs.uk/rightcare/wp-content/uploads/sites/40/2017/11/rightcare-pathway-diabetes-reasonable-adjustments-learning-disability-2.pdf

The General Medical Council

www.gmc-uk.org/learningdisabilities

The Royal College of General Practitioners

www.rcgp.org.uk/learningdisabilities

Mencap

www.mencap.org.uk/learning-disability-explained/resources-healthcare-professionals

Public Health England

www.gov.uk/government/publications/reasonable-adjustments-for-people-with-learning-disabilities

NHS England Guides to help staff support people with access needs

www.england.nhs.uk/publication/guides-to-help-staff-support-people-with-access-needs

Down's Syndrome Association

www.downs-syndrome.org.uk/for-professionals/health-medical/annual-health-check-information-for-gps

National Autistic Society

www.autism.org.uk/professionals/health-workers.aspx

Useful reading

For people with a learning disability and their supporters

Bradford Talking Media

www.btm.org.uk/resource-category/health

Easyhealth

www.easyhealth.org.uk

Mencap

www.mencap.org.uk/advice-and-support/health/our-health-guides

Down's Syndrome Association

www.downs-syndrome.org.uk/for-people-with-downs-syndrome/health

NHS Choices

www.nhs.uk/LiveWell/Disability/Pages/Disabilityhome.aspx

Your Health Matters – Leeds

www.yourhealthmatters-leeds.nhs.uk

Acknowledgments

Diabetes UK would like to thank Louise Bryant, Allan House, Amy Russell, Vicky Ward, Catherine Stones and Karl Witty from the University of Leeds who developed this guide.

Our thanks also go to Sam Browning, Matt Hoghton, Zoe Neill, Paul Carder, Lynne Carter, Dominic Slowie, Jane Kachika, Mencap, CHANGE, easy on the i and the Down's Syndrome Association for their generous time and support.

The content of this guide was informed by research funded by the NIHR (OK Diabetes, HTA ref: 10/102/03). The production of this guide was funded by Diabetes UK, the University of Leeds and the Health Foundation. The Health Foundation is an independent charity committed to bringing about better health and health care for people in the UK.



To download this guide visit www.diabetes.org.uk/learning-disability

To download our other guides visit www.diabetes.org.uk/how-to-guides



For more information about making reasonable adjustments to diabetes care for adults with a learning disability email sharedpractice@diabetes.org.uk

www.diabetes.org.uk

A charity registered in England and Wales (215199) and in Scotland (SC039136). © Diabetes UK 2018 1316.