

# Making reasonable adjustments to diabetes services for people with learning disabilities: What nurses can do

Susan Turner

People with learning disabilities are more likely to have diabetes than the general population and need more support to manage the condition, but, conversely, this group is less likely to get good diabetes care. Access to services can be improved by altering the services to meet individual needs (reasonable adjustments) – something that public sector organisations have a duty to do under the 2010 Equality Act. While a number of good practice examples exist, much still needs to be done, and nurses working in the field have an important role to play. Where possible, people with learning disabilities should be supported to manage their diabetes and accessible information should be readily available to facilitate understanding. Specialist learning disability services are an excellent source of knowledge, and working with them to provide tailored education and support can be very effective. Implementing a culture of reasonable adjustments may also benefit other people who struggle to access services.

This article summarises what we know about people with both learning disabilities and diabetes, describes some problems with detecting and diagnosing diabetes, and sets out some actions that nurses can take to enable people with learning disabilities to access diabetes services and manage their condition more effectively.

A number of the source documents used in the writing of this article come from the Improving Health and Lives Learning Disabilities Public Health Observatory (now part of Public Health England), and use data and information from England. However, the issues discussed are applicable to all health services across the UK.

## Defining learning disability

People with a learning disability have:

- A significantly reduced ability to understand

new or complex information, and to learn new skills (impaired intelligence).

- A reduced ability to cope independently (impaired social functioning).

The disability will have been apparent before adulthood, with a lasting effect on development (Department of Health [DH], 2001).

## People with learning disabilities and diabetes

People with learning disabilities make up approximately 2% of the population in the UK (Emerson and Hatton, 2004). People with learning disabilities are more likely to have diabetes than the general population. Data from GP information systems in England reveal higher rates of type 1 and type 2 diabetes and lower rates of retinal screening among people with learning disabilities who have diabetes (Emerson et al, 2012). The higher rate of type 2

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## Article points

1. People with learning disabilities are more likely to have diabetes than the general population and need more support to manage the condition.
2. Access to services can be improved by altering services to meet individual needs (reasonable adjustments).
3. Nurses have an important role to play in enabling people with learning disabilities to access diabetes services and manage their condition more effectively.

## Key words

- Diabetes services
- Learning disability
- Reasonable adjustments

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### Page points

1. People with learning disabilities may have poor awareness of their own bodies and how they work, and may not understand the significance of signs and symptoms related to the onset of diabetes.
2. Ensuring that people with learning disabilities and their carers have sufficient information on the signs and symptoms of diabetes and encouraging the uptake of annual health checks are two actions that nurses can take to support people with learning disabilities.
3. In 2012/13, just over half of all people with learning disabilities who were eligible for an annual health check received one.

diabetes is likely to be related to increased levels of obesity in people with learning disabilities; women, people with Down's syndrome, people living in less restrictive environments and people with mild learning disabilities are particularly at risk.

People with learning disabilities often have a poor diet and do little in the way of exercise. Also, research has shown that carers generally have poor knowledge about public health recommendations for a healthy diet (Emerson et al, 2012).

Emergency admissions to hospital for the complications of diabetes are proportionally higher among people with learning disabilities compared with the general population (Glover and Evison, 2013). Complications of diabetes are classed as an ambulatory care sensitive condition (ACSC). This means it is a condition that can normally be treated effectively in primary care, and thus admission to hospital for this ACSC indicates potential weaknesses in primary care that need investigation (Glover and Evison, 2013).

### Diagnosing diabetes in people with learning disabilities

People with learning disabilities may have poor awareness of their own bodies and how they work, and may not understand the significance of signs and symptoms related to the onset of diabetes. Limited communication skills may also make it hard for people with learning disabilities to tell others how they are feeling in a way that can be easily understood (Emerson et al, 2012). This makes it important for carers, both paid and unpaid, to identify health needs and recognise when people are unwell. Unfortunately, studies show that carers do not feel confident about identifying health needs, and may not pick up on behaviours that indicate a health need (Emerson et al, 2012).

In order to address unmet health needs, the Department of Health introduced annual health checks for people with learning disabilities in 2009. Clinical commissioning groups (formerly primary care trusts) are required to offer GP practices the opportunity to carry out annual health checks under a directed enhanced service

(DES). Participating practices have a DES register of people with learning disabilities who are also known to social care – a small proportion of the total number of people with learning disabilities (Glover, 2013).

There is clear evidence that health checks detect unmet health needs and lead to actions to address them (Robertson et al, 2010). Chauhan et al (2012) also noted that the implementation of annual health checks was associated with significant coding activity for Quality and Outcomes Framework (QOF) incentivised health screening, promotion and disease finding, including diabetes. However, in 2012/13 just over half of all people with learning disabilities eligible for a check received one (Glover, 2013).

Diagnosing type 1 diabetes can also be problematic, as one carer noted:

*“My son, who has learning disabilities, was diagnosed with type 1 diabetes when he was 9 years old. It took a couple of weeks to diagnose, as at first the GP thought it was a urinary tract infection. Diagnosis can take a long time for some young people and they can become very ill before the correct diagnosis is given. It is really important for families and GPs to be aware of the signs and symptoms of type 1 diabetes, so that it can be picked up early.”*

It is important for nurses to be aware of these issues, particularly in light of the higher rates of hospital admission for complications of diabetes described above. Ensuring that people with learning disabilities and their carers have sufficient information on the signs and symptoms of diabetes (see below) and encouraging the uptake of annual health checks by people with learning disabilities are two actions that nurses can take.

### How nurses can support people with learning disabilities to manage their diabetes

Without the right support it can be difficult for people with learning disabilities to manage their diabetes. Putting reasonable adjustments in place to enable people with learning disabilities

to access services and understand their condition is very important.

Reasonable adjustments refers to the changes that need to be made to services so that they work as well for people with learning disabilities as they do for the general population. Adjustments may include changing policies and procedures and providing staff training (Hatton et al, 2011). Making reasonable adjustments is a legal requirement for public services under the Equality Act 2010 (UK Parliament, 2010a) and Health and Social Care Act 2008 (UK Parliament, 2010b). This requirement should be anticipatory, meaning that healthcare professionals should consider in advance the reasonable adjustments they need to make to ensure that their services are accessible.

When possible, people with learning disabilities should be supported to understand and manage their diabetes. A recent study on self-management of diabetes by people with learning disabilities found that even for those with a good understanding of the condition, the quality of support they received was crucial (Hale et al, 2011). The researchers recommended the use of a personal plan for each individual, along with accessible

information and peer-led education.

Accessible information designed to help people with learning disabilities understand and manage their diabetes, including accessible health action plans, is available on a number of websites for nurses to use (see *Box 1*).

### Learning disability services

In some areas, specialist learning disability services and the diabetes team work together to develop training and support for people with learning disabilities. These initiatives can be particularly helpful.

Turner and Emerson (2013) cite an example in Northamptonshire, where the diabetes team and specialist learning disability nurses worked together to develop a “Looking after me and my diabetes” course for people with learning disabilities and either type 1 or type 2 diabetes. The course has been running for 6 years and is delivered by the diabetes team as part of the overall diabetes education programme. It is based on the principles of self-management and is designed to be accessible, using easy words, pictures and lots of other visual aids during sessions to aid communication and understanding. The course content covers:

- What diabetes is.
- Healthy eating.
- Physical activity.
- Medication management.
- The importance of health checks.

It is helpful if the person with a learning disability invites a carer who can attend the course with them and is able to offer support outside the course and in the long term. During the course, participants start a health action plan for managing their diabetes, and carers on the course are asked to complete a support plan setting out how they are going to support the individual.

### Addressing fears

Nurses should also recognise that some people with learning disabilities are frightened of healthcare professionals. Heslop et al (2013) found that almost a sixth of the people whose deaths they reviewed had a significant fear of healthcare professionals. The confidential

### Page points

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2. In some areas, specialist learning disability services and the diabetes team work together to develop training and support for people with learning disabilities. These initiatives can be particularly helpful.
3. Nurses should recognise that some people with learning disabilities are frightened of healthcare professionals, perhaps because of previous poor or distressing experiences.

#### Box 1. Useful resources for nurses working with people with learning disabilities and diabetes.

- Easyhealth is a website that provides accessible health information for people with learning disabilities: [www.easyhealth.org.uk](http://www.easyhealth.org.uk)
- A Picture of Health provides Easy Read information: [www.apictureofhealth.southwest.nhs.uk](http://www.apictureofhealth.southwest.nhs.uk)
- Public Health England provides a database of useful documents for healthcare professionals: [www.ihal.org.uk/adjustments/](http://www.ihal.org.uk/adjustments/)
- Information about diabetic retinopathy is available on the SeeAbility website: [www.seeability.org](http://www.seeability.org)
- Diabetes UK have a video designed for use with people with learning disabilities: [www.diabetesdvd.org.uk](http://www.diabetesdvd.org.uk)

**“Despite the resources available, people with learning disabilities still struggle to access health services. Nurses are well placed to improve the situation, making a big difference to the lives of people with learning disabilities and their families.”**

inquiry carried out by Heslop et al (2013) found that this fear of healthcare professionals was a contributing factor in a number of premature deaths.

People with learning disabilities may be afraid of healthcare professionals because of previous poor or distressing experiences. The mother of the boy with type 1 diabetes (described previously) gave this description of what happened when her son was diagnosed:

*“After a few days I realised the only thing the staff could think of was to hold him down to take bloods, do finger pricks and give insulin. Eventually I suggested we make some picture cards (PECS [picture exchange communication system]) for him that helped to explain why he had to have injections now and also gave him incentives to sit still to have them. Some play therapy was incorporated, but it was sporadic and not really age appropriate. We should have been given advice and counselling at the beginning.”*

There are a number of ways to address people’s fears, including desensitisation techniques, that can be used very effectively. The boy in the case study above is now giving himself insulin injections. As mentioned previously, local specialist learning disability services can offer advice and help at this stage.

### Conclusion

There are a number of reasonable adjustments that can be made to support people with learning disabilities who have diabetes to access appropriate services and manage their condition. Many are easily downloadable from websites and can be adapted for local use (see *Box 1*).

Despite the resources available, people with learning disabilities still struggle to access health services. Nurses are well placed to improve the situation and make a big difference to the lives of people with learning disabilities and their families. Reasonable adjustments that people with learning disabilities find helpful may also benefit other people who struggle to access services, such as people from black and minority ethnic groups and people with low levels of literacy. ■

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