

# Diabetic eye screening in people with learning disabilities: Improving access

Rachel Pilling

**Research has shown that there are higher rates of type 1 and type 2 diabetes in people with learning disabilities. All people with diabetes should undergo eye screening at the time of diagnosis and annually thereafter, and digital photography-based screening is now established as a diabetes service in all four nations of the UK to ensure that the condition is promptly identified and treated before vision is affected. Research has also shown that there are lower rates of retinal screening among people with learning disabilities and diabetes. This article discusses the importance of eye screening for people with learning disabilities and diabetes and gives an overview of a recent audit carried out in Bradford Royal Infirmary looking at the current processes in eye screening for this group of people with diabetes.**

Adults with learning disabilities are thought to account for a significant proportion of the number of people with diabetes in the UK (Reichard and Stolze, 2011). Data from GP information systems in England also indicate higher rates of type 1 and type 2 diabetes among people with learning disabilities (Glover et al, 2012). This may be due to the association of diabetes with certain conditions, such as Down's syndrome and Prada-Willi syndrome, and the higher rates of obesity in people with learning disability (Emerson, 2005).

Glover et al (2012) also found that in England there are lower rates of retinal screening among people with learning disabilities who have diabetes.

All adults with diabetes over 18 years should have their eyes screened at the time of a diabetes diagnosis and annually thereafter to improve identification of cases with sight-threatening retinopathy (NICE, 2008). Currently, children over 12 years are also offered screening (NICE,

2008). Digital photography-based screening is now established as a diabetes service in all four nations of UK to ensure that the condition is promptly identified and treated before vision is affected. The Equality Act (2010) requires that publicly provided services make reasonable adjustments to allow those with learning disabilities improved access to services and equality of care (UK Parliament, 2010). The aim is to remove some of the many barriers that prevent those with disabilities from accessing services (Turner et al, 2012; Emerson and Turner, 2013).

This article discusses the importance of eye screening for people with learning disabilities and diabetes and gives an overview of a recent audit carried out in Bradford Royal Infirmary looking at the current processes in eye screening for this group of people with diabetes (Pilling, 2014).

## Methods

By cross referencing data from the local

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## Article points

1. Data from GP information systems in England indicate higher rates of type 1 and type 2 diabetes among people with learning disabilities and also lower rates of retinal screening in these groups.
2. An audit was carried out in Bradford Royal Infirmary looking at the current processes in eye screening for this group of people with diabetes and it was found that 35% of their study group did not have a recorded screening outcome.
3. Common themes were identified in order to improve uptake, including the need to highlight disability and promote access; provide the best information and make appointments as comfortable as possible for the person with learning disabilities and their carers.

## Key words

- Diabetes
- Learning disability
- Diabetic eye screening

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### Page points

1. An audit carried out in Bradford Royal Infirmary identified 71 adults with a learning disability and diabetes; 35% of people did not have a recorded screening outcome.
2. Most of the problems that people with learning disability and their carers encounter stem from the fact that services do not know they have a learning disability or require reasonable adjustments prior to their arrival in clinic.
3. Health professionals can benefit if the community learning disability team helps with the planning of appointments and also attends appointments alongside people with learning disabilities and their carers.

community health facilitation team in Bradford and the diabetic retinal screening database, we were able to identify people with both diabetes and a learning disability. We analysed the screening outcomes to determine if this group of people was being screened regularly. The rationale behind the audit was to identify how uptake of screening services might be improved.

A total of 71 adults with a learning disability and diabetes were identified. Unfortunately, under half of these had any note of their learning disability identified on the diabetic retinal screening database, which may prevent the relevant healthcare professionals providing any necessary additional support prior to the appointment. Despite these findings, the audit found that 91% of those with both a learning disability and diabetes had been offered diabetic retinal screening; this included 77% being offered screening in the community and 14% within the hospital eye service.

Despite these encouraging numbers, 35% of people did not have a recorded screening outcome. Of those individuals known to the community diabetic eye screening programme (DESP), 26% had never completed a diabetic eye disease examination. Reasons for this included:

- Failure to attend appointments (16%).
- Being labelled as “unsuitable” by the GP (6%).
- Individual attending the appointment but attempts to obtain photographs were not successful (3%).
- Failure to be offered an appointment (1%).

Analysis of those individuals known to the hospital service indicated that only three of the 14 individuals who were unable to complete photographic screening had been offered an alternative screening method.

### Common themes

We reviewed these outcomes with the community health facilitation team, the DESP manager and patient representatives. Some common themes became clear and these were analysed in order to develop a set of reasonable adjustments to reduce the inequality in uptake for those with learning disabilities. These

themes are discussed below.

### Highlighting the disability

Most of the problems that people with learning disability and their carers encounter stem from the fact that services do not know they have a learning disability or require reasonable adjustments prior to their arrival in clinic. Most screening databases have a “cognitive status” field that can be used to highlight learning disability to those professionals who are arranging appointments. Therefore, the audit team suggest that liaising with local learning disability health facilitation teams to identify individuals with learning disability and diabetes may improve engagement with appointments.

Health professionals can benefit if the community learning disability team helps with the planning of appointments and also attends appointments alongside people with learning disabilities and their carers. The input of these teams regarding reasonable adjustments to services can help facilitate the smooth running of clinic visits.

The role of carers attending appointments should not be underestimated. Carers will often know the person with learning disabilities very well and will be able to alert the healthcare professional when the person is becoming very agitated and to offer a break in the examination. For example, I have seen an individual who made loud noises throughout her visit and the carer was able to inform me that this was her typical behaviour at home; however, when she began to thump her chest, this was a sign that she was becoming distressed and we stopped the examination. Similarly, carers are able to tell us if the individual with learning disabilities becomes distressed in the dark, so we would avoid turning the lights off during the examination.

People who can become aggressive can be accompanied by two carers who are trained to support the individual in these circumstances; they are able to monitor the individual to see if they are distressed and take necessary action to prevent harm or injury to the patient or the healthcare professional.

**Promoting access**

Occasionally, individuals with a learning disability are excluded from screening programmes on the assumption that they will not be able to comply. Before this judgement is made, reasonable adjustments should be explored, as many individuals can undergo some form of screening with appropriate support. Routinely referring all people with a learning disability to the hospital eye service may not be a suitable solution as often these appointments are further from home and involve a long wait in a busy clinic area. Supporting individuals locally is more likely to lead to success.

**Information**

SeeAbility, which is a charity that supports visually impaired people with learning disabilities, has produced an Easy Read information leaflet for both people with learning disabilities and their carers (SeeAbility,

2011). This leaflet explains the importance of screening and describes using pictures what happens at a screening appointment. Supplying these leaflets to people with learning disabilities at diagnosis can help understanding and engagement with the screening programme.

**Desensitisation**

Some people with a learning disability can become overwhelmed and anxious in a new environment, and this can be true of a visit to an eye screening clinic. If their carer is also unsure of what to expect, preparing for a visit can be difficult. Offering an opportunity to visit the screening room prior to the appointment can make the experience less daunting for both the individual with diabetes and their carers.

**Additional time**

People with learning disabilities may also

**Page points**

1. Routinely referring all people with a learning disability to the hospital eye service may not be a suitable solution as often these appointments are further from home and involve a long wait in a busy clinic area.
2. Some people with a learning disability can become overwhelmed and anxious in a new environment. Offering an opportunity to visit the screening room prior to the appointment can make the experience less daunting for both the individual with diabetes and their carers.
3. People with learning disabilities may also become anxious if they feel rushed. Offering a double appointment will allow more time for the vision assessment, as well as the photograph test.

**Case study 1: Mohammed and his brother**

Mohammed, who has moderate learning disability, was brought by his brother to a community diabetic eye screening test. He struggles to know his letters, so had a picture vision test instead. At first he was reluctant to put his chin on the machine for the photograph and would only sit on the chair beside it. Mohammed's brother suggested bringing him back another time to see if he was more cooperative, as it would not be all so new to him second time around. The appointments centre used Mohammed's brother's phone number to arrange a time when they could come back together and photographs were successfully taken on the next visit.

**Case study 2: Pauline and the community learning disability team.**

Pauline has severe learning disability. At first Pauline failed to attend screening appointments as her carer thought that, because of her limited communication, she would not be able to benefit from the test, assuming it was for glasses. The carer also felt that as she had no concerns about Pauline's vision and there was no need for a screening appointment. The community team went to visit Pauline and her carer at home. They took some Easy Read information to explain that screening takes place to identify problems before sight loss occurs. They also explained that Pauline would not have to read any letters. They showed some pictures of the equipment that would be used to take the photographs. The community team liaised with the appointments centre to arrange a double appointment to give Pauline enough time to explore the room before having her photograph. The team also arranged to be present on the day of the screening visit to support the technician and so Pauline had two familiar faces to help her to a successful visit.

**“Liaison with local health facilitation teams is key to identifying these individuals before they are sent a screening appointment in order to plan the visit and discuss what adjustments might be needed.”**

become anxious if they feel rushed. Offering a double appointment will allow more time for the vision assessment, as well as the photograph test. The screening technician is also under less pressure and a successful outcome more likely at the first visit. If the healthcare professional feels that more time is needed, it is appropriate to offer a repeat appointment, as often the individual is more relaxed on subsequent visits.

### Case studies

The two case studies shown on the previous page show how making careful adjustments to the eye screening process can make a significant difference in improving uptake. The individuals discussed in the case studies have been given false names to protect their identity.

### Conclusion

Liaison with local health facilitation teams is key to identifying these individuals before they are sent a screening appointment in order to plan the visit and discuss what adjustments might be needed. Referral to hospital eye care for screening creates more barriers to patients than community care. The majority of adults with learning disability can access health services with reasonable adjustments and allowing a little more time can make the difference in enabling equality of care for this vulnerable group of people with diabetes. ■

#### Resources

- Seeability: [www.seeability.org](http://www.seeability.org)
- Improving health and lives learning disabilities observatory (Public Health England): [www.improvinghealthandlives.org.uk](http://www.improvinghealthandlives.org.uk)

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