Adults with learning disabilities are 10 times more likely to experience serious sight loss than other people. They are also more likely to experience health inequalities, including being at a higher risk of health conditions, such as diabetes. Aylee Richmond, Senior Eye Care Advisor at SeeAbility, discusses the barriers to involving this group in diabetic eye screening and ways in which these could be overcome.
Both Type 1 and Type 2 diabetes are among people with a learning disability who also have diabetes, and we also know that this group is likely to have more difficulty in managing their diabetes. Diabetic eye screening presents a number of challenges for this client group. However, it is important that these challenges are addressed to give people with learning disabilities the best chance of managing their eye health.

Barriers to diabetic eye screening can include a general lack of awareness of the importance of eye screening and a belief that sight tests and diabetic eye screening are the same thing. People with complex needs find many medical appointments difficult. This could be due to problems understanding and processing instructions, fear that the procedure will hurt, memory of previous poor experiences and needing to interact with complete strangers. It is also important to remember that people with learning disabilities can be reliant on family carers or paid support staff to enable them to attend appointments, which can sometimes cause difficulties. For example, carers may make assumptions that someone who is unable to communicate, or has difficulty reading, may be unable to undergo a vision test and disregard the screening invitation. They may also think that, if the person has had a sight test, they do not need to go for a retinal screen, confusing the two.

Optometric sight tests have a domiciliary option, which can make the process easier for those people that struggle to get out of the house; if diabetic eye screening had a similar option, this could make screening more accessible.

Diabetic screening pathways are designed for the general population, and do not currently facilitate the best chance of managing their eye health. This makes the process difficult as people with learning disabilities are expected to fit in with services that are not designed to meet their needs. In addition to the above barriers, many health services still do not provide information in accessible formats, despite there now being a legal obligation to do so. NHS England introduced the Accessible Information Standard in 2016, which gave NHS services and social care a legal obligation to provide information in accessible formats when required.

Another significant barrier to overcome is the lack of flagging systems for identification of patients with learning disabilities. For diabetic screening services to be more flexible, they need to know when patients with learning disabilities have appointments. Many NHS providers still lack robust flagging systems, which would identify patients with complex needs and give clinics a better chance of meeting those needs. We know that diabetic eye screening services want to do more to help patients. However, systems need to change to allow this to happen.

"Optometric sight tests have a domiciliary option to help people who struggle to get out of the house; if diabetic eye screening had something similar, this would make it more accessible."

What is the impact of non-attendance at eye screening in this community?

One of SeeAbility’s aims is to prevent unnecessary sight loss. With diabetes being a leading cause of preventable sight loss in the UK, we are keen to ensure that people with complex needs have regular diabetic eye screening to prevent avoidable blindness. If this vulnerable group of people is not accessing screening appointments, this could lead to irreversible sight loss and some patients not being able to communicate concerns or fully understand what is happening to them. It appears that people with learning disabilities, who also have diabetes, are less likely than the general population with diabetes to have had retinal screening (49% compared to 56%). Also, there is the question of what happens to those people with complex needs who have unsuccessful screening, or those who have been unable to access screening services. Referral to an eye clinic may not be the best option for most people with learning disabilities, as these can often be crowded and time-pressured. People with learning disabilities are likely to be unable to attend appointments, through no fault of their own, and potentially be discharged from diabetic eye screening services. If this happens, they are less likely to be able to self-refer back into the system.

The impact of diabetic eye disease could also lead to changes in behaviour that carers or supporters may not realise are related to changes in vision. Behavioural changes could be displays of frustration, fear and/or becoming withdrawn. This can have a substantial effect on quality of life, perhaps leading to a need for increased support from paid or family carers, and a higher risk of falls.

How can these barriers be reduced?

The Equality Act 2010 requires organisations to make "reasonable adjustments", in order for those with disabilities of any kind to access services. In most cases, people with learning disabilities would benefit from reasonable adjustments within their appointment and the generic standardised pathway for diabetic eye screening does not routinely offer this. Reasonable adjustments can include:

- longer appointment times
- more than one attempt/appointment
- use of accessible information (in line with the NHS Accessible Information Standard)
- alternative visual acuity tests, such as Kay Pictures and Cardiff cards
- training in communicating with people who have learning disabilities
- providing desensitisation sessions, which helps people with learning disabilities to become more familiar with the screening process
- additional time to practice and understand the practical aspects of the screening test.

Accessible information promotes a greater level of understanding of medical procedures and appointments. This can include appointment letters, results letters and information booklets. For most people with learning disabilities, the most accessible format is easy-read.
The NDTi and SeeAbility are very much aware of the issues around diabetic eye screening for people with learning disability, and agree that change is needed. Easy-read is written with uncomplicated sentences and pictures, which helps people to understand information. Identifying patients with learning disabilities attending diabetic eye screening services is crucial to ensure that reasonable adjustments are made. Flagging systems are not always available, although this would be the ideal method to identify patients. It is important to ensure that GPs are making referrals which include information about the person’s learning disability. This could be achieved by greater engagement between the GP surgery and diabetic screening services. Another useful resource that can help with identifying patients with complex needs is a Hospital Passport. These are designed for people with learning disabilities to help share important information about their health, communication, likes and dislikes. We know that generic health services do not always meet the needs of people with learning disabilities, which is why serious consideration should be given to establishing a dedicated learning disability pathway. This would create an easier environment for health services, such as diabetic eye screening services, as it would enable practitioners to give more time, with less pressure, dedicated clinic time (such as a day or half day once a month), built-in reasonable adjustments, training for practitioners and routine accessible information.

There is also support available from learning disability specialists within NHS trusts, such as the Acute Learning Disability Liaison Nurses and the community learning disability team. They support people with learning disabilities to access mainstream health services. We strongly recommend that diabetic eye screening services engage with them to ensure better outcomes for people with learning disabilities.

What is the role of organisations like the National Development Team for Inclusion (NDTi) and SeeAbility? And how are you working together on this?

Both we and the NDTi (www.ndti.org.uk) have a shared vision to create an equal right to sight for people with learning disabilities. We have collaborated on a variety of eye care resources, including a guide about reasonable adjustments in eye care presentations, events and blogs. SeeAbility and the NDTi are very much aware of the issues surrounding diabetic eye screening for people with learning disabilities, and we agree that the system needs to change. Our approach is to work together when needed and highlight the issues, with a view to supporting screeners and embedding good practice.

What is your vision for improving attendance at eye screening in those with a learning disability?

We want to see equitable, well-planned and high-quality eye care services that are truly inclusive of the needs of people with learning disabilities. Diabetic eye screening is an essential part of managing eye health for those with diabetes, and we hope to see more people with complex needs attending reasonably adjusted appointments and fewer people developing diabetic eye disease which could have been prevented.

What’s your take-home message for Update readers – whether or not they are directly involved in eye screening?

We have a variety of messages for healthcare professionals involved in any way in diabetic eye screening for people who have a learning disability.

- We want eye care services to be aware that adults with learning disabilities are 10 times more likely to have serious sight loss, and that people with learning disabilities are also at more risk of developing diabetes, which could have substantial implications for their eye health.
- We would also like to highlight the need for accessible information, and ask that diabetic eye screening services strive to deliver this.

Can you list some resources that would help us learn more about this issue?

There are many resources available that can help. These include:

- SeeAbility’s easy-read information at www.seeability.org/diabetic-eye-screening.
- SeeAbility’s easy-read factsheet on eye drops, which could be useful for familiarisation with patients at www.seeability.org/eye-drops-factsheet.
- SeeAbility’s functional vision assessment tool – a resource that can be used by parents/carers to find out more about how a person sees on a functional (not clinical) basis at www.seeability.org/fva.
- Hospital Passports – always ask the person or their supporter if they have a Hospital Passport, as this will help to understand their needs at www.easyhealth.org.uk/listing/hospital-passports-leaflets.

What is SeeAbility?

SeeAbility is a charity providing specialist support, accommodation and eye care help for people with learning disabilities, autism and sight loss.
The team at East Anglian Diabetic Eye Screening Programme (EADESP) presents their recent Learning Disability Audit and describes the successful implementation of some new measures.

We aim to ensure health equality by identifying our patient cohort. This means that each register captures those with a learning disability appropriately, consistently, and is maintained and up-to-date. We capture the “read code” from the GP (the sole referrer into EADESP), which would be the national code for a learning disability. Our GPs have signed data sharing agreements to ensure we extract these codes. The programme has an engagement team, which is responsible for the accuracy of this list and is a point of contact for patients and their carers. This also ensures that the correct patients are flagged on the software system.

Patients can be manually identified as having a learning disability within the screening software by the screening team. If a code has been missed, or patient is thought to have a learning disability, the GP notifies the engagement team directly. We then liaise with the GP and IT, giving the person an identification flag.

To be able to implement interventions and reasonable adjustments there is a need for clear identification of patients with a learning disability within the EADESP software. This means that:

- engagement managers are able to identify patients six to eight weeks before an appointment due date
- the bookings team is able to identify patients when scheduling appointments
- the screener is able to identify patients at appointments.

This allows us to apply reasonable adjustments to our clinics. In EADESP we use a mixture of the following, when needs have been identified:

- Extra appointment time. We can block appointments either side of the patient and extend the appointment time to as long as is deemed necessary
- Pre-visits. Patients and carers can come and visit the venue, look at the camera, meet the screening/reception staff and so on. This visit would be headed by management/engagement. This also covers desensitisation work.
- Training of staff with alternate vision charts, with SeeAbility presenting to our multidisciplinary team.
- Availability and use of different picture charts – Kay, E, Sheridan Gardner.
- Easy-read letters and documentation sent to patients. We use SeeAbility’s documents and our own. We are now looking at customising our own documentation with images specific to East Anglia.
- Ability to refer to learning disability specialist nurses for external support. Connecting with the wider learning disability team for advice/best practice.
- Liaising with GP practices.
The anticipated introduction of biennial screening for low-risk patients is also likely to improve the service for those with complex needs. Moving some patients from annual screening to a two-year interval will free up capacity. Local programmes are being encouraged to use these extra resources to focus on vulnerable and hard-to-reach groups.

The Service Specification for the NHS Diabetic Eye Screening Programme states that providers should deliver screening in a way that addresses local health inequalities and supports vulnerable or hard-to-reach groups, including those with learning disabilities. Local DESPs have been working hard to achieve this goal for many years and, since the introduction of the Accessible Information Standard in 2016, this work has only increased.

As the case study above shows, there are steps that local providers can take to better meet the needs of individuals with learning disabilities and the EADESP is just one of many programmes working to identify methods of achieving this. The British Association of Retinal Screening aims to facilitate the sharing of best practice by organising regular Failsafe Forums, where providers can discuss these challenges and share solutions, helping each other to make screening more accessible for those with complex needs.

In 2017, the national diabetic eye screening data set was updated to include additional fields for disabilities and special requirements, allowing DESPs to record information relating to learning disabilities within the screening software. Public Health England has produced an easy-read version of the standard leaflet about diabetic eye screening (www.gov.uk/government/publications/diabetic-eye-screening-easy-read-guide) and every DESP can use this when appropriate, along with simple steps, such as booking longer appointments for those who need them.

The challenge, however, lies in identifying these individuals before they attend for screening, so that appropriate measures can be put in place. Work is under way to address this, with Public Health England aiming to include some information on learning disabilities in the GP2DRS system, which shares patient data between GP practices and DESPs, while NHS Digital is working on a Reasonable Adjustment lag to be available on an individual’s Summary Care Record. These are ongoing projects, but will hopefully improve the identification of people with learning disabilities in the near future.

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The implementation of this change to DES intervals is being led by NHS England, with the aim of piloting biennial screening at a number of pathfinder sites next year. Public Health England is currently revising the national pathway standards in preparation for this change, which will also require significant updates to the screening software and the implementation of an education and training plan for DESP staff and communications to patients.

Once in place, this modification to the way screening is delivered should provide DESPs with even more opportunity to address health inequalities and put additional measures in place to improve screening for people with learning disabilities.

REFERENCES
• Search ‘people with a learning disability’ at www.diabetes.org.uk for access to our suite of resources on diabetes care for this group.