Improving eye care for people with learning disabilities: SeeAbility policy position statement

SeeAbility is the national charity that exists to support people with sight loss and multiple disabilities. The charity has expanded in recent years to use its expertise to address the public eye health inequalities that people with learning disabilities experience. SeeAbility has a policy position statement on the need to provide specialist sight tests for children in special schools: this statement concentrates on eye care for adults with a learning disability.

What we think: people with learning disabilities experience greater risk of sight problems and need good quality eye care

People with learning disabilities are at a greatly increased risk of sight problems. Research has estimated the number of people with learning disabilities and sight problems in the UK:

- Adults with a learning disability are 10 times more likely to have a serious sight problem than other adults.
- 579,000 adults with a learning disability have refractive error. This means 6 out 10 people with learning disabilities need glasses.
- An estimated 96,500 adults with learning disabilities are blind or partially sighted. This is about 1 in 10 of the adult learning disabilities population.

The high prevalence of sight problems in people with learning disabilities may be due to cerebral visual impairment (vision processing in the brain), optic atrophy (damage to the optic nerve), high refractive error (astigmatism, short or long sightedness), amblyopia (reduced vision), strabismus (squint/eye turn), cataracts (clouding of the lens in the eye), nystagmus (involuntary eye movements), keratoconus (progressive changes to the shape of the eye’s outermost layer) or developmental abnormalities of the eye.

There is evidence that the more profound and complex the learning disability, the greater the visual impairment. Certain conditions also make it more likely that individuals will experience sight problems or eye health disorders. Juvenile Batten Disease first presents in children and young people through degenerating sight. People with Down’s Syndrome are at high risk of eye disorders including strabismus, cataracts, and keratoconus. As people with learning disabilities get older the prevalence of sight problems grows, as will the risk of age related macular degeneration which is a cause of significant sight loss. It has been suggested that all persons with severe or profound intellectual disabilities, and all older adults with Down’s syndrome, should be considered visually impaired until proved otherwise.

1 Please see www.seeability.org.uk/childreninfocus
5 Van Splunder et al. As above
What’s happening now: people with learning disabilities are missing out on the eye care they need

Good sight is vital for a person’s independence and daily life. Regular sight tests are recommended for different age groups to identify issues and take any action needed. More targeted surveillance of the eyesight of adults with learning disabilities is endorsed by experts. Despite this, people with learning disabilities are missing out on the eye care they need. Many individuals are living with poor vision just for want of a pair of glasses. There are tragic cases of people who have lost their sight due to a blinding eye condition that has been unnoticed for many years or identified too late.

Visual impairment diminishes the independence of people with learning disabilities, can even increase the risk of self-injury, may put people at greater risk of accidents and falls, or in need of more costly packages of support from health and social care.

In a recent evaluation of a SeeAbility project supporting people with learning disabilities a third of patients had a new eye health issue identified from their sight tests, and 6 in 10 received new or replacement glasses. For 50% of patients the date of their previous sight test was more than 2 years ago or unknown. Many of the people who had their sight tested were over 60 years old, and significantly some 10% of patients were referred on for cataract surgery, with smaller numbers being referred on for glaucoma or diabetes-related eye health concerns.

In another study providing vision screening in day centres, over half of individuals could have benefitted from glasses. A telephone survey of nearly 150 adults with learning disabilities found 39% were receiving less eye care than the general population.

Some of the underlying reasons for poorer access and outcomes for people with learning disabilities include:

A lack of identification and awareness of likelihood of eye problems
Reporting of sight problems is often symptom-led, so this puts people with more profound and multiple disabilities at risk of not getting the eye care they need. People may not realise they have a sight problem nor be able to tell someone about it. Someone’s behaviour may be wrongly attributed to the diagnosis of a learning disability. Those who know the person best may think they can see perfectly well, or that the person could not complete a “typical” sight test.

Lack of signposting and reasonable adjustments
People with learning disabilities may not know how to access a service to meet their needs or may be concerned about having a sight test. People with learning disabilities say that they value good

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communication, having tests explained to them and being given extra time. Simple and low cost adjustments are available – for example, information in easy read format or the use of pictures. Yet these reasonable adjustments to sight testing practice can be overlooked despite legal duties to make services more accessible\textsuperscript{13} and there is a low awareness of the ability to ask for a sight test in their more familiar home or in a care setting if it would help the person feel less stressed.

There is also evidence that inequalities exist in onward access to certification and registration processes, to allow people to access greater support for daily living, as well as further treatment and eye surgery. This might be because of assumptions about the benefit to the person or their ability to comply with treatment or give consent.

**Concerns about costs of tests and glasses**
There is no automatic right to a free sight test or glasses vouchers in this high risk group of adults. It means some people with learning disabilities can prefer to go to hospital eye clinics, which can deliver a sight test for free, risking longer waiting times. This is also more expensive to the NHS.

There is a repair and replacement vouchers scheme if the damage is due to a person’s illness\textsuperscript{14} but the person will still be without glasses in this time. A person with a learning disability may benefit from having easy access to a spare pair of glasses or flexible frames in case of damage. Nor do the main funding rules allow for prescribing of frames to fit special facial characteristics.

**A lack of data**
There is no data collected on access to eye care by people with learning disabilities, so there is no understanding of the eye health outcomes they experience at a local or national level. For example, the Certificate of Vision Impairment (CVI) does not have a specific “flag” that a person has a learning disability, nor does the form that captures information on a NHS sight test. There is no data on how many people with learning disabilities are accessing “reasonably adjusted” services to provide eye tests at home, in residential/day care settings\textsuperscript{15} or in hospital eye clinics.

**Sight is not a priority in health checks**
The evidence is that only around half of people with learning disabilities eligible for an annual health check with their GP receive them and implementation remains variable\textsuperscript{16}. Prompts on vision and getting a sight test are listed in the health check, but many people are still not being told about sight tests\textsuperscript{17}. Rates of diabetes are higher in the population with learning disabilities but there is evidence that diabetic screening – key to preventing sight loss due to diabetes – is failing to adequately monitor people with learning disabilities\textsuperscript{18}.

**What should happen: eye care for people with learning disabilities must be reformed**

SeeAbility and others run individual projects to improve eye care for people with learning disabilities, but further reform is needed to reduce the eye health inequalities that people

\textsuperscript{13} Improving Health and Lives (2013). Making reasonable adjustments to eye care services for people with learning disabilities.
\textsuperscript{14} See Section 16 (3)(b) National Health Service (Optical Charges and Payments) Regulations 2013
\textsuperscript{15} Hansard written question answered 5 March 2015
experience. People with learning disabilities have the same rights of access to NHS services as everyone else and reasonable adjustments should be made to meet their needs under law.¹⁹

Local reform recommendations
Locally, a variety of health bodies and providers are responsible for services. We recommend:

- Health commissioners and Local Eye Health Networks recognise the eye care needs of those with learning disabilities in their local strategies (Joint Strategic Needs Assessments and Eye Health Needs Assessments).
- Health commissioners evaluate the effectiveness of their local eye care services - working with people with learning disabilities to report on their experiences and identify solutions.
- Every Clinical Commissioning Group should adopt a community eye care learning disability pathway. These pathways raise awareness and signpost people with learning disabilities and their supporters to good eye care, train optometrists and provide reasonably adjusted sight tests to transform people’s sight.²⁰
- Investment in Learning Disability Nurses who can support individuals to access treatment and surgery.
- Ensuring there are well established procedures in every hospital for assessing consent and capacity, and reasonable adjustments to practice, so people do not lose the opportunity for eye care treatment and surgery.

National reform recommendations
Nationally, the government, the NHS and public health policymakers need to thoroughly review the way in which they approach eye care for people with learning disabilities. We recommend:

- National recognition of the importance of eye care for people with learning disabilities – for example in national public health strategies and outcome indicators for the NHS and public health.
- Ensuring the emotional impact and consequences of sight loss for those with a learning disability are recognised– for example through implementation of new national guidelines.
- Improved entitlement to free sight tests and glasses for adults with learning disabilities. Receipt of disability benefits could be better linked to eligibility, and the GOS system should be reformed so that people get spare glasses and special frames to meet their needs.
- A reform of GOS, Certificates of Visual Impairment and Hospital Eye Clinic records to better capture patient data for learning disabilities.
- Health and social care training to include eye care for at risk groups, particularly as professionals are often the “gatekeepers” for further screening and treatment and ensuring that optometrists have the confidence to meet people’s needs.
- National monitoring of GPs’ promotion of regular eye care at annual health checks.
- Increased awareness of the availability of domiciliary sight testing, but this needs to be preceded by a review by NHS England of access and standards of domiciliary practice.

Read more: www.seeability.org/sharing-knowledge
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¹⁹ For example, the Health and Social Care Act 2012 provides a duty on health bodies to reduce inequalities in terms of both access to health services and the outcomes people experience.
²⁰ Local Optical Committee Support Unit (2013) Community Eye Care for Adults and Young People with Learning Disabilities Pathway.