Vision and People with Learning Disabilities: Guidance for GPs
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This guidance aims to support GPs and primary health care teams to identify sight loss and visual impairment in their patients with learning disabilities to signpost them to appropriate specialist services.

Key Facts about vision and people with learning disabilities¹

There are approximately 1 million adults in the United Kingdom with a learning disability:

- People with learning disabilities are 10 times more likely to have serious sight problems than other people. People with severe or profound learning disabilities are most likely to have sight problems.

- People with learning disabilities may not know they have a sight problem and may not be able to tell people. Many people may think the person with a learning disability they know can see perfectly well.

- 6 in 10 people with learning disabilities need glasses and often need support to get used to them.

- People with learning disabilities need to have a sight test every two years, sometimes more often. Regular sight tests and wearing glasses helps people stay healthy and get the most from life.

Sight is the key to learning, communication and movement. If someone already has problems in these areas, then a visual impairment may have more of an impact. A change in visual function may not be easily communicated by people with learning disabilities. It may manifest itself in withdrawal or as a change in behaviour.

¹ Public health messages derived from research published by Emerson and Robertson, Centre for Disability Research (CeDR) at Lancaster University. Commissioned by SeeAbility and RNIB and endorsed by Mencap, Vision 2020 UK and the DoH.
The most common cause of visual impairment is refractive error; for many people with learning disabilities a pair of glasses is all that is required to improve their visual function and, by implication, their social function, independence and quality of life.

It is a widely held misconception that if someone can’t read, they don’t need good vision. Everyone needs adequate vision to help them with everyday activities: to choose clothes, identify and close fastenings; to see what food is on their plate and know what it is they are eating; to prepare drinks and see how much water is in the kettle; to recognise people talking to them and interpret facial expressions.

Signs and symptoms

Unidentified sight problems can seriously undermine quality of life and lead to avoidable sight loss and increased dependency. Some people with learning disabilities may exhibit adverse behavioural changes as a result of impaired vision. This is because they have difficulties expressing themselves.

What you can do

Familiarise yourself with the list below. Be aware of how people with learning disabilities might present and consider visual loss as a cause for a change in behaviour.

Examples of signs and symptoms associated with eye problems in people with learning disabilities

- Eye poking or rubbing
- Persistently red eyes
- Discomfort with bright lights
- Anxiety in unfamiliar situations
- Hesitancy in poorly lit environments, especially on steps or at pavement edges
- Unwillingness to venture out of their immediate environment or be involved
- Depression, anger or frustration
- Reduction in social or domestic skills and participation
- Loss of interest in family, friends, TV or social activities
- Undue alarm at unfamiliar noises or when approached
- Bumping into furniture or accidentally knocking over cups
Communication and accessible information

What you can do

When communicating with people with learning disabilities consider the following strategies:

Guidance on communication with people with learning disabilities

- Talk to the person, not their supporter or carer
- Speak slowly and clearly
- Explain procedures in easy words
- Explain and/or demonstrate the equipment to be used
- Do not touch people without warning – give them time to show they have consented to being examined
- Do not hurry people – they may get upset and less willing to co-operate
- Check the person has understood and give them the opportunity to ask questions if necessary

People with learning disabilities may need extra time to understand or think about options presented to them. They may also need support from a carer and easy read information.

A range of easy read factsheets on eye care and vision are available on SeeAbility’s website www.seeability.org

This easy read information uses plain language and illustrations to explain the different parts of an eye examination.
Routine eye tests and Annual Health Checks for people with learning disabilities

People with learning disabilities should be enabled to have routine eye tests every two years, or more frequently if necessary. However, they may not self-refer when visual problems occur or may not know how to access services. If sight loss is gradual, the person affected, carers and family members may not notice changes in behaviour. Behavioural changes may be noted but misinterpreted as deterioration in general health or attributed to the learning disability itself, ageing or dementia. Many conditions amenable to treatment may be left to a point at which treatment is no longer useful. Treatable ophthalmic conditions such as cataracts may result in months or years of needless discomfort, confusion and distress if the signs and symptoms are missed or misinterpreted.

SeeAbility’s easy read literature is available to help patients prepare for an eye test so they are better able to anticipate what will happen. Some people with learning disabilities will require more than one visit to gain trust and confidence to enable a full examination to take place.

What you can do

Asking about problems with vision is part of the annual health check for people with moderate and severe learning disabilities. If there are any concerns about a patient’s eye health, a change in vision, or if a patient has not seen an optometrist (optician) in the last two years, the GP should recommend the patient attends the optometrist for a test. SeeAbility’s easy read literature explains what happens at the optometrist’s and the “Telling the Optometrist about Me” form will also help the patient and carer to prepare.

There are many local services which provide support enabling people with learning disabilities to gain access to eye tests. Many optometrists have training in assessing people with learning disabilities. If glasses are prescribed, a period of adjustment, adaptation and support is essential. Both the purpose of the glasses and most appropriate times for them to be worn need to be clearly explained to the patient and carer. Advice is available on SeeAbility’s website.
Some hospital eye departments have specialist clinics for screening by an orthoptist, or a multi-disciplinary clinic with other specialists. With appropriate support and planning, successful surgical outcomes can be achieved. The fact that someone has learning disabilities should not be a barrier to referral for eye surgery.

When referring a patient to the hospital eye clinic, it is important to mention that the person has learning disabilities and the specific reason for referral. This will help the hospital to allocate the person to the appropriate clinic and enable them to consider what reasonable adjustment to make for the individual.

The SeeAbility website has a database of local optometrists and details of local enhanced services that offer longer appointment times and repeat visits to complete procedures where needed.

**A case study**

Sally is 32 years old and lives with her dad, her brother and her mum, Maureen, in Barking, London. Sally has a rare genetic condition called 18P-Syndrome which is linked to issues including small ears, small nose bridge, curvature of the spine, epilepsy and learning disabilities. People with 18P-Syndrome are thought to be more at risk of developing glaucoma. This condition often develops without obvious symptoms: an eye examination is the only way to detect glaucoma early so action can be taken to prevent unnecessary sight loss.

Around five years ago, Sally started rubbing her eyes. Maureen took her to the doctors and the GP prescribed drops for hay fever. The symptoms did not go away and Sally described an “itch” on her head, her way of saying she had a headache. Her head became sensitive to touch: Maureen took her back to the GP who suggested Sally had either a thyroid or scalp problem. There was no suggestion of any eye problems at this stage.

At Christmas, Sally’s brother gave Sally a sweet and as she went to take it she missed. This was when Maureen first thought that there could be a serious problem with her vision. Maureen decided to try and test her theory of a potential sight problem and used the coloured sweets called Skittles. She spread them over a table and asked Sally to pick them up. Sally swept her hand over the sweets; she found them by touching them, not by seeing them.

Maureen took Sally for a sight test and the test revealed that Sally had extremely high pressures in both eyes and was losing her sight. The Optometrist recommended that Sally be taken to the accident and emergency department immediately. Maureen took Sally: staff found it difficult to examine her and
asked her to return the next day to see a consultant ophthalmologist. At this appointment, Sally was diagnosed with glaucoma and was urgently referred to Moorfields Eye Hospital.

At Moorfields different treatment options were considered. Laser treatment was unsuccessful and Sally was then booked in for an operation to insert a tube to help drain fluid from her eye. The surgery was successful in managing the glaucoma and bringing down Sally’s dangerously high eye pressures, but sadly, she had already lost almost all her vision. Sally can now only see light and dark. Maureen says, “We feel guilty about Sally’s eye condition. We wish we’d noticed it earlier. We wish we’d had more awareness of sight problems amongst people with learning disabilities.”

Although Sally has been through a terrible ordeal, she has now adapted well through having the support of her family, day centre and health professionals.

Maureen’s top tips for other carers:

• Get your own eyes tested, and make sure the people you are caring for have an eye test every two years, or more often if needed
• Don’t be worried, talk about your concerns with health professionals
• Talk to the optometrist before an appointment and check the facilities
• Remember that people with learning disabilities are 10 times more likely to have sight problems than other people

Maureen’s top tips for health professionals:

• Listen to what carers say
• Find out information on eye conditions linked with learning disabilities
• Sally’s sight loss could have been avoided – remember carers might need awareness training on sight problems
This guidance was created by the Royal College of Ophthalmologists in conjunction with SeeAbility.

About SeeAbility

SeeAbility is a registered charity which specialises in supporting people who have multiple disabilities, including sight loss, learning and physical disabilities, mental health difficulties and life limiting conditions. Originally founded as The Royal School for the Blind in 1799, SeeAbility has a heritage dating back over 200 years and are the leading experts in this sector.

SeeAbility’s eye 2 eye Campaign has transformed eye care and vision for people who have learning disabilities across the UK. Please visit www.seeability.org

About The Royal College of Ophthalmologists

The College champions excellence in the practice of ophthalmology for the benefit of patients and the public. The College also sets the examinations and the curriculum for medical graduates who wish to be eye surgeons and in addition, provides elements of surgical skills training. The College sets the standard for professional practice through clinical guidelines and ophthalmic service guidelines. The continuing professional development (CPD) programme is designed to help ophthalmologists maintain and increase their knowledge and expertise.

The College has a role in promoting ground-breaking research; in organising a seminar programme and an annual scientific congress and producing the scientific journal EYE, to disseminate that research.
For further information, please visit www.rcophth.ac.uk

About The Royal College of General Practitioners

Since the de-institutionalisation of the care of people with a learning disability GPs have a greater responsibility in care of people with learning disabilities. The RCGP has identified learning disabilities as a key clinical priority because of the impact of health inequalities on people with a learning disabilities.

Dr Matt Hoghton, the RCGP Clinical Champion for Learning Disabilities, and the RCGP Learning Disabilities Professional Network continue to produce e-learning modules and other materials to help GPs and primary healthcare teams to provide high quality care, including annual health checks.
For further information, please visit www.rcgp.org.uk/learningdisabilities
Further information and resources

Contact SeeAbility for information or advice by emailing SeeAbility’s eye 2 eye Campaign team on eye2eye@seeability.org

www.seeability.org

SeeAbility’s website has a wealth of information about access to eye care and vision services for people with learning disabilities. Easy read information is available, including:

- Having an eye test
- Choosing the right glasses
- Telling the Optometrist about Me – a form to be completed and taken to an eye test
- Feedback from the Optometrist about My Eye Test – a form to make sure people know about what the optometrist advises and recommends after an eye test
- Having a cataract operation

Other resources on the website include:

- Functional Vision Assessment – an observational tool which can be used to recognise how a person with learning disabilities might be using their sight
- Optometrists database - a database of optometry practices who have registered to support people with a learning disability to have an eye test
- Eye surgery support plan
- 10 times more likely – a short film about the high prevalence of sight problems amongst people with learning disabilities

Recognising the need to improve access to good eye care services, the new “Community Eye Care Pathway for Adults and Young People with Learning Disabilities” has been developed by the Local Optical Committee Support Unit (LOCSU) in conjunction with SeeAbility and Mencap. The Pathway gives Local and Regional Optical Committees the basis for a proposal to improve the way eye care for people with learning disabilities is delivered in their local area. The enhanced sight test described in the pathway is delivered in a community setting and the longer test time gives optometrists more time to familiarise patients and their carer with the procedures and equipment at the time of the sight test and also gives time for repeat visits to complete procedures where needed.

www.locsu.co.uk/enhanced-services-pathways/community-eye-care-pathway-for-adults-and-young-pe
SeeAbility is the operating name of the Royal School for the Blind founded in 1799. Registered Charity No. 255913.