People with learning disabilities and eye care

What every Local Eye Health Network (LEHN) and Local Optical Committee (LOC) needs to know

People with learning disabilities are at increased risk of sight problems

Let’s look at the stats.

An estimated 96,500 adults with learning disabilities are blind or partially sighted in the UK. This is about 1 in 10 of the adult learning disabilities population in the UK.

Adults with a learning disability are 10 times more likely to have a serious sight problem than other adults.

For children the likelihood is higher as sight problems are comparatively rare in the general population of children.

>1 million adults with learning disabilities in the UK.

579,000 adults and nearly 200,000 children with learning disabilities have refractive error in the UK. This means around 6 out 10 adults with learning disabilities in the UK need glasses.

These figures will rise by approximately 0.5% each year over the next two decades.

For more information see Emerson and Robertson (2011). The estimated prevalence of visual impairment among people with learning disabilities in the UK. Published by RNIB and SeeAbility www.seeability.org/uploads/files/PDFs_Books_non_Easy_Read/PWLD_VI_prevalence_report.pdf.
They are also less likely to get the eye care they need

People with learning disabilities are less likely to get the eye care they need because they may not know where to go to get appropriate eye care, or wrong assumptions are made about whether they have a sight problem:

In work undertaken with adults with learning disabilities in west London a third of patients had a new eye health issue identified from their sight tests, and six in ten received new or replacement glasses. For 50% of patients the date of their previous sight test was more than 2 years ago or unknown. 10% were referred on for cataract surgery.

Research with children in special schools has found that nearly four in ten (37%) of pupils had no history of eye tests. Related research has found as many as half of the pupils in special schools may need glasses.

There are tragic cases of people with learning disabilities who have lost their sight due to an eye condition that has been unnoticed for many years or identified too late.

How many people with learning disabilities live in the LEHN/LOC area?

There is no national data collection on the number of people with learning disabilities, but it is estimated about 2% of the population has a learning disability.

Public Health England hosts information by local authority and commissioning group area based on prevalence estimates for adults and children; how many people with learning disabilities are known to services; and how many access an annual health check. See Learning Disability Profiles http://fingertips.phe.org.uk/profile/learning-disabilities.

The Health and Social Care Information Centre also collates data on the number of adults with learning disabilities who are on GP registers (although please note, this may not be a true reflection of the total population number). www.hscic.gov.uk/article/2021/Website-Search?productid=16273&q=stroke&sort=Relevance&size=10&page=2&area=both#top.

The Centre also collects figures on numbers of people who are registered blind and partially sighted, who are also recorded as having a learning disability. This is recorded by local authority area www.hscic.gov.uk/catalogue/PUB14798. Again please note, uptake of registration amongst people with learning disabilities may be lower than expected, so these figures are likely to under-represent true numbers.
How the LEHN/LOC can help

Large numbers of people with learning disabilities are not presenting for eye care.

To remedy this:

- Put eye care for people with learning disabilities on the agenda at your meetings.
- Recommend in Eye Health Needs Assessments improvements to community sight tests for people with learning disabilities. For those over 14 years of age, the LOCSU community eye care pathway for people with learning disabilities has been successfully piloted in a number of areas and provides trained optometrists, reasonably adjusted appointments and support and accessible information for the individual. See [www.locsu.co.uk/community-services-pathways/community-eye-care-pathway-for-adults-and-young-pe](http://www.locsu.co.uk/community-services-pathways/community-eye-care-pathway-for-adults-and-young-pe).
- Recommend in Eye Health Needs Assessments targeted work in special schools where this is not already taking place, so children get a comprehensive specialist sight test when they first start special school (which we recommend is a joint optometric and orthoptic assessment), and then an annual specialist sight test (or more often if recommended) performed in the familiar surroundings of their special school. See [www.seeability.org/childreninfocus](http://www.seeability.org/childreninfocus).

This will help:

- Deliver the LEHN and England Vision Strategy ambition to improve access and detect eye conditions early in hard to reach groups.
- Meet a key aim of the NHS England Business Plan to transform care for people with learning disabilities.
- Save on wider health and social care costs reducing numbers of people being seen in hospital for regular sight tests, or preventing high level health and social care needs from untreated sight loss.

How SeeAbility can assist LEHNs/LOCs

Freely downloadable resources

SeeAbility offers easy read information for adults with learning disabilities on eye care, wearing glasses, and eye conditions. This information includes forms that adults and their supporters can fill in before an eye test “Telling the optometrist about me”, and easy read feedback forms that optometrists can use. Our bookshelf of information can be found at: [www.seeability.org/sharing-knowledge](http://www.seeability.org/sharing-knowledge).

We also offer many similar resources on eye care and vision for children with learning disabilities including information for parents. [www.seeability.org/childreninfocus](http://www.seeability.org/childreninfocus).

SeeAbility is able to advise on how eye care information can be enhanced to meet new NHS Accessible Information Standards.
Working with people with learning disabilities

SeeAbility can also assist your LEHN to engage with people with learning disabilities. We have an easy read questionnaire for people with learning disabilities that you can use to gauge their experiences of local eye care services.

We have Look Here events we run with people with learning disabilities to raise awareness of looking after your eyesight. Watch our promotional film here www.seeability.org/our-services/advisory-services/?article=look-here-events.

Working with eye care professionals

Training for eye care professionals is also available. We also have a database which hosts optometrists and dispensing opticians that can offer support to people with learning disabilities, that LEHNs and LOCs can help promote www.seeability.org/our-services/find-optometrist.

Working with commissioners

We are able to work with CCGs and LEHNs to ensure that the LOCSU adults with learning disabilities pathway is put in place in local areas to enhance uptake of eye care. www.seeability.org/who-we-are/media-centre/research/community-eye-care.

Working with health/social care staff

We are able to advise on how to link up with health promotion work within learning disability services and run a range of courses for supporters and professionals who work with people who have a learning disability around eye care and vision. www.seeability.org/our-services/advisory-services.

Share your work with us

Getting eye care right for people with learning disabilities should mean you get it right for everyone. Please let us know if you have good practice you would like to share.

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