

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.

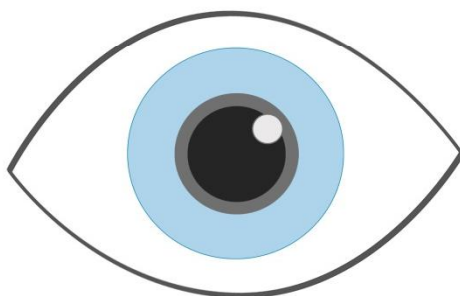


An estimated **105,000** people with learning disabilities are blind or partially sighted in England.


This is about **1 in 10** of the learning disabilities population in England.

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

10x



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



28 times



504,796 adults in England or **6 out of 10 adults in England**

with learning disabilities have refractive error ie will need glasses.

Tens of thousands of children with learning disabilities are also affected.

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 **four in ten (43%) of pupils had no history of eye tests.** Related research has found **half of pupils in special schools** have a problem with their eyesight.

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. The following sources may also be helpful:

Public Health England hosts information by upper tier local authority based on prevalence estimates for adults and school age 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>. Estimates for adults with learning disabilities by upper tier authority can also be sourced by registering with the “Projecting Adult Needs” site at www.pansi.org.uk.

NHS Digital also collates data on the number of adults with learning disabilities who are on GP registers by CCG (*although please note not all people with learning disabilities are registered with their GP and this may not be a true reflection of the total population number*). See <http://digital.nhs.uk/catalogue/PUB18887/qof-1415-ccg-all.xlsx>

NHS Digital 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 at <http://digital.nhs.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. See Ability would be happy to present to your LEHN to assist your discussions.
- 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.
- Recommend in Eye Health Needs Assessments targeted work in special schools where this is not already taking place, so children get an annual specialist sight test (or more often if recommended) in the familiar surroundings of their special school. See www.seeability.org/childreninfocus. A recommended framework for a special schools service, supported by the main clinical bodies involved in children's eye care can be found at: www.seeability.org/uploads/files/Children_in_Focus_campaign/Framework.pdf

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 NHS England to **transform care for people with learning disabilities and reduce preventable sight loss**.
- ✓ 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 including easy read

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. SeeAbility is able to advise on how eye care information can be enhanced to meet new NHS Accessible Information Standards which were implemented on 31 July 2016: www.seeability.org/accessible-information-standard.

Our full bookshelf of information can be found at: 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.

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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