

# Eye care for people with learning disabilities: SeeAbility position statement (non-easy read)



[Our easy read statement.](#)

## Introduction

SeeAbility is the national charity that exists to support people with learning disabilities and autism, many of whom have sight loss. The charity uses its expertise to address the public eye health inequalities that people with learning disabilities experience, campaigning for an 'Equal Right to Sight'.

In July 2016 we published a report called 'Delivering an equal right to sight'<sup>1</sup>, which sets out our calls for reform in more detail. Since then Public Health England has published a guide on making reasonable adjustments in eye care for people with learning disabilities<sup>2</sup> and NHS England has committed to improve eye care for children with learning disabilities in its Long Term Plan.<sup>3</sup>

This 2022 policy statement assesses the progress made and sets out the outstanding calls for reform for **everyone** with a learning disability. It reflects SeeAbility's new eye care strategy.<sup>4</sup>

New NHS ambitions for learning disabilities and eye care outpatient transformation, wider reforms to integrate health and social care, public health reforms, a review of the special educational needs system, eye care regulatory changes and training proposals, all potentially underpinned by legislation, mean this is the right time to renew our call for an "Equal Right to Sight".

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<sup>1</sup> See [Delivering an Equal Right to Sight](#)

<sup>2</sup> See [Eye care and people with learning disabilities: making reasonable adjustments - GOV.UK \(www.gov.uk\)](#)

<sup>3</sup> See [NHS Long Term Plan » Online version of the NHS Long Term Plan](#)

<sup>4</sup> See [Eye Care and Vision Strategy 2021-2023 | SeeAbility](#)

## Case for reform

### 1) 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<sup>5</sup> 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, about 1 in 10 of the adult population will be blind or partially sighted.
- **6 in 10 people** with learning disabilities need glasses.
- Children with learning disabilities are **28 times more likely** to have a serious sight problem than other children (as visual impairment is very low incidence in the general population of children).

One paper reviewed all the research and said '**every study describes an alarming level of blindness and visual impairment**'.<sup>6</sup>

Sight problems are even more common amongst people with more severe or profound and multiple learning disabilities, or with particular syndromes associated with a learning disability such as Down's Syndrome. Recently a study of over 1,000 people with learning disabilities found 47% had a vision problem – it was **the most prevalent** physical or sensory condition that people had alongside their learning disability, and prevalence rose with severity of learning disability.<sup>7</sup>

In fact, 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 proven otherwise.**'<sup>8</sup>

In some cases, these sight problems may be congenital with Cerebral Visual Impairment (the processing of vision by the brain) now the most common cause of visual impairment in children, often in those with additional neurodisabilities.<sup>9</sup>

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<sup>5</sup> Emerson and Robertson (2011) The Estimated Prevalence of Visual Impairment among People with Learning Disability in the UK. Our updated figures for 2021 from this study are that 105,831 adults with learning disabilities are blind or partially sighted and 616,664 people need glasses. See [seeability.org/about-us/reports-and-research](https://seeability.org/about-us/reports-and-research)

<sup>6</sup> See [Visual impairment in adult people with intellectual disability: Literature review - Warburg - 2001 - Journal of Intellectual Disability Research - Wiley Online Library](#)

<sup>7</sup> See [Prevalence of physical conditions and multimorbidity in a cohort of adults with intellectual disabilities with and without Down syndrome: cross-sectional study | BMJ Open](#)

<sup>8</sup> See [Prevalence of visual impairment in adults with intellectual disabilities in the Netherlands: cross-sectional study | Eye \(nature.com\)](#)

<sup>9</sup> See [Visual impairment, severe visual impairment, and blindness in children in Britain \(BCVIS2\): a national observational study - The Lancet Child & Adolescent Health](#)

In special schools, which the majority of children with severe and profound learning disabilities attend, half of pupils have a vision problem.<sup>10</sup>

However, as we all age our risk of having a sight problem grows, and this is as true for people with learning disabilities too. People with learning disabilities also experience higher levels of comorbidities, such as diabetes<sup>11</sup> and poverty.<sup>12</sup> Again, these are all associated risk factors for sight problems, and there are also proven socioeconomic barriers in accessing sight tests.<sup>13</sup>

An investigation into the early deaths of people with learning disabilities (the 'CIPOLD inquiry') found that 50% of people who died prematurely had a vision problem<sup>14</sup>, which is at its very least an indication of prevalence.

## **2) People with learning disabilities are still missing out on the eye care they need.**

Good sight plays a crucial role in promoting a person's independence in everyday life. Regular sight tests are recommended for different age groups to identify issues and take any action, which could be as straightforward as a prescription for glasses. Support for sight loss might also include access to treatments and surgery or include rehabilitation for visual impairment, assistive technology and mobility support, as well as support to come to terms with diagnosis.

More targeted surveillance of the eyesight of people with learning disabilities is endorsed by health experts and researchers. There is evidence that visual impairment diminishes the independence of people with learning disabilities and may put people at greater risk of behavioural challenges, accidents and falls, or in need of more costly packages of support from health and social care.<sup>15, 16, 17, 18</sup>

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. This includes children with learning disabilities who could have benefitted from interventions much earlier on to help their eyesight develop.

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<sup>10</sup> See [Findings from an opt-in eye examination service in English special schools. Is vision screening effective for this population? \(plos.org\)](https://doi.org/10.1186/14752875)

<sup>11</sup> See Diabetes UK [Improving care for people with diabetes and a learning disability - Fact sheet 1.pdf](#)

<sup>12</sup> For example see [Poverty and people with intellectual disabilities - Emerson - 2007 - Mental Retardation and Developmental Disabilities Research Reviews - Wiley Online Library](#)

<sup>13</sup> See Health Survey England <http://content.digital.nhs.uk/catalogue/PUB16076/HSE2013-Ch3-eye-care.pdf>

<sup>14</sup> See CIPOLD [fullfinalreport.pdf \(bristol.ac.uk\)](#)

<sup>15</sup> See [Does visual impairment lead to additional disability in adults with intellectual disabilities? - PubMed \(nih.gov\)](#)

<sup>16</sup> See [A vicious circle: visual impairment in people with learning disabilities | Nursing Times](#)

<sup>17</sup> See [Visual loss and falls: a review - PubMed \(nih.gov\)](#)

<sup>18</sup> See [Physical conditions and challenging behaviour in people with intellectual disability: a systematic review - de Winter - 2011 - Journal of Intellectual Disability Research - Wiley Online Library](#)

- For around half of adults with learning disabilities the date of their previous sight test was more than 2 years ago or unknown.<sup>19,20</sup>
- A situation that is replicated for children with learning disabilities with evidence that over 4 in 10 children in special schools have no history of eye care at all.<sup>21</sup>
- Only 5,775 people with learning disabilities are on the blind or partially sighted registers with their local authority in England<sup>22</sup>, which is much less than the 1 in 10 estimated to have a serious sight problem.

### 3) Why is this happening?

More comprehensive evidence for poorer access and outcomes have been outlined in the Public Health England document **Eye Care and Reasonable Adjustments for people with learning disabilities**.<sup>23</sup> These include:

#### **A lack of identification and awareness of likelihood of eye problems**

Reporting a sight problem is often symptom-led, and 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, known as 'diagnostic overshadowing'. Those who know the person best may think they can see perfectly well. There is evidence and studies showing that vision needs of children and adults are frequently underreported in their specialist settings.<sup>24</sup>

There can be misconceptions that someone has to be able to speak or read to have a sight test, or that getting a sight test or making use of glasses may be too distressing or upsetting for that person.<sup>25,26,27</sup> In common with the general population, the importance of regular sight tests, even if you don't think you have a problem, might also be underestimated.

#### **Lack of signposting and reasonable adjustments**

<sup>19</sup> See [SeeAbility's LOCSU LD Pathway London Tri-borough FINAL REPORT 0.PDF](#)

<sup>20</sup> See [Improving Eye Care Across Wessex | Healthwatch](#)

<sup>21</sup> See [Findings from an opt-in eye examination service in English special schools. Is vision screening effective for this population? \(plos.org\)](#)

<sup>22</sup> See NHS Digital February 2021 [Registered Blind and Partially Sighted People, England 2019-20 - NHS Digital](#)

<sup>23</sup> See Public Health England 2020. [Public Health England 2020](#)

<sup>24</sup> See [A lack of vision: evidence for poor communication of visual problems and support needs in education statements/plans for children with SEN - ScienceDirect](#)

<sup>25</sup> See [Sensory Impairment in Adults With Intellectual Disabilities—An Exploration of the Awareness and Practices of Social Care Providers - Newsam - 2010 - Journal of Policy and Practice in Intellectual Disabilities - Wiley Online Library](#)

<sup>26</sup> See [Vision awareness training for health and social care professionals working with people with intellectual disabilities: Post-training outcomes - Joanne Dick, Janet Finlayson, June Neil, Linda Mitchell, Nicola Robinson, 2015 \(sagepub.com\)](#)

<sup>27</sup> See [The challenges of providing eye care for adults with intellectual disabilities - PubMed \(nih.gov\)](#)

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 say that they value good communication, easy read information, having tests explained to them and being given extra time. Seeing the same eye care professional is also helpful, to build up familiarity.<sup>28</sup>

Reasonable adjustments to sight testing practice can be overlooked despite legal duties to make services more accessible or professionals themselves may need additional training. Anecdotally there appears to be a low awareness of the ability to ask for a sight test at home or in a care setting for those who have great difficulty attending a community optical practice. Sometimes there is confusion over what is 'screening' and a full sight test – diabetic eye screening for example is not a full sight test.<sup>29</sup>

### **Concerns about costs of tests and glasses**

Eligibility for NHS sight tests under secondary legislation has also missed out people with learning disabilities in the exclusive list of groups who are eligible (children, older adults, people in receipt of certain means tested benefits, and 'high risk' groups such as those with a family history of glaucoma, or diabetes).<sup>30</sup> This places the burden on the person with a learning disability to work out if they are eligible in other ways.

Faced by confusing rules on potential entitlement to a NHS funded sight test and glasses vouchers, it means people can be worried about what they have to pay, which aligns with other findings on the public perception of the retail nature of optical care. It means some people with learning disabilities and their families can prefer to go to hospital eye clinics. The impact of cuts to support time could also mean people having to prioritise what health appointments they make.

### **Low priority in learning disability and eye care policy and programmes**

Not being listed as a high risk group in NHS systems (such as sight tests) means there is very little 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. While prompts on vision and getting a

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<sup>28</sup> See [Improving Eye Care Across Wessex | Healthwatch](#)

<sup>29</sup> See [Diabetic retinopathy tests accessible to adults with learning disabilities? \(nationalelfservice.net\)](#)

<sup>30</sup> Under [The Primary Ophthalmic Services Regulations 2008 \(legislation.gov.uk\)](#) the following groups are eligible for NHS sight tests as part of mandatory or additional services (domiciliary):

- children and older adults (over 60 years of age).
- Being registered blind or partially sighted
- Being a prisoner
- 'high risk' groups - such as having a family history of glaucoma or suffering from diabetes (although others are listed no mention of learning disability)
- People in receipt of certain means tested benefits.

sight test are listed in the GP annual learning disability health check, the question is not always asked and nor may it be open to a GP to make a referral for a sight test.<sup>31,32</sup> Rates of diabetes are higher in the population with learning disabilities but there is also evidence that diabetic eye screening is failing to adequately monitor people with learning disabilities.<sup>33</sup>

Meanwhile the NHS has a drive to reduce face to face outpatient attendances by nearly a third and eye care is one of three speciality priorities, as ophthalmology is the one of the busiest. This means a push towards patients following up their own appointments, or accessing advice and consultations digitally. But some people are digitally excluded and the onus on patients with learning disabilities to make these arrangements and follow ups in secondary care is not being sufficiently addressed in these new national programmes.

## **System barriers**

NHS England operates a national budget and contract for NHS funded sight tests and help towards the cost of glasses, the General Ophthalmic Services or 'GOS' contract, but this has remained largely unchanged for many years, including a fee of circa £22 paid to optometrists for a sight test in a practice or day centre.

This fee structure does not take account of the fact that those with learning disabilities may need longer or multiple appointments in community optical practices or other settings, such as special schools. Only in Scotland has a new national sight testing fee been introduced for those with complex needs.<sup>34</sup>

### **4) Have there been recent developments in eye care for people with learning disabilities?**

In our [Delivering an Equal Right to Sight report](#) we highlighted the incredible work that has been happening across the country to improve access to eye care for people with learning disabilities. That work continues by people with learning disabilities, their supporters and many eye care professionals and policymakers.

In 2019 SeeAbility established a new [Eye Care Champion programme](#), employing people with learning disabilities and autism to raise awareness of the importance of going for sight tests. To date the Champions have reached thousands of people

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<sup>31</sup> See [An evaluation of the effectiveness of annual health checks and quality of health care for adults with intellectual disability: an observational study using a primary care database \(nih.gov\)](#)

<sup>32</sup> See [Assessment of an incentivised scheme to provide annual health checks in primary care for adults with intellectual disability: a longitudinal cohort study - The Lancet Psychiatry](#)

<sup>33</sup> See [Diabetic eye screening in people with learning disabilities: Improving access - DiabetesontheNet](#)

<sup>34</sup> See [www.sehd.scot.nhs.uk/pca/PCA2018\(O\)02.pdf](#)

with learning disabilities, their supporters and professionals and promoted the use of accessible information in eye care.

On reforms there have been key developments, including, but not limited to:

### **Launch of an NHS special schools eye care service**

To NHS England's credit, in 2019 it committed to rollout a programme of sight testing for children in special schools (supported by a clinical framework paper). This is a multidisciplinary service, bolstering existing services in special schools, and providing eye care where there has been none previously.<sup>35</sup>

Children are receiving an NHS sight test, glasses (if needed) and a report on their visual abilities. At the time of writing, having been interrupted by the Covid 19 pandemic, the programme is in three regions of the country in day and residential special schools. Ongoing evaluation of the data so far confirms a large proportion of children have never had any eye care before the service. However, it is currently unclear how committed NHS England are to a full rollout of this service nationally, for all special schools.

### **LOCSU community eye care pathway**

In some areas of the country there have been efforts to improve access in the community too, with refreshed LOCSU community pathways, endorsed by SeeAbility and Mencap<sup>36</sup> established in Cheshire and Merseyside, Greater Manchester, Durham and Sutton and ongoing work in other regions. This enables practices to sign up to providing 'enhanced' support which allows for a 'top up' of the current £22.14 NHS sight test contract fee to see patients who might face the most barriers to getting a full sight test.

Despite it making good use of primary care to support outpatient eye care transformation, with recommended referral criteria<sup>37</sup> to reduce the need for people with learning disabilities to rely on hospital eye clinics, this is not a 'high volume' service in comparison to other eye care needs and so not a priority workstream in the outpatient programme. Without national mandate/direction by the NHS it means that the service is not available everywhere.

### **Prioritisation in public health and training**

Improvements in data collection are starting to be made with information now collected through Certification of Visual Impairment on patients with a learning disability. Early analysis shows the heterogeneity of the types of vision problems that people with learning disabilities are experiencing. The Office for Health

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<sup>35</sup> See [www.nhsbsa.nhs.uk/what-we-do/special-school-eye-care-service](http://www.nhsbsa.nhs.uk/what-we-do/special-school-eye-care-service)

<sup>36</sup> See [Refreshed clinical pathway for People with Learning Disabilities now available - LOCSU](#)

<sup>37</sup> See [Referral thresholds for an integrated learning disability eye care pathway: a consensus approach | Eye \(nature.com\)](#)

Improvement and Disparities has also dedicated a chapter of its new Atlas of Eye Health Variation<sup>38</sup> to focus on the needs of those with learning disabilities to aid commissioning, and has made recommendations for reform.

Professional guidelines and training are also continuously highlighting the need to ensure people with learning disabilities do not lose the opportunity for eye care. NHS guidance issued in 2019 recognises that sometimes it is not possible for all elements of a sight test to be completed for a person, and a recent review of education for student optometrists and dispensing opticians requires demonstrating experience in testing patients with more “complex” needs, and making necessary adjustments.

### **5) What policy reforms are still needed to improve eye care for people with learning disabilities?**

We all have a part to play in improving access to eye care for the hundreds of thousands of people with learning disabilities who experience poor vision and who could be at risk of unnecessary sight loss. 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.

However, policy reform is also needed to reduce the eye health inequalities that people experience. With new structures locally and opportunities nationally to support both eye care and learning disability support, our recommendations for policymakers are as follows:

- All people with learning disabilities should be entitled to an NHS funded sight test rather than work out their eligibility in other ways. This would provide a clear public health message, that people with learning disabilities are at increased risk of eye disease, and so eligible for NHS sight tests as of right.
- Our recommendation is that this is annual, to align with frequency for other high risk groups and align with the GP annual health check. The GP check should have an improved section on eyesight so GPs can remind people of the ability to access a free sight test at their annual check, and also make a referral to a local community eye care pathway (see below) if it was felt this is what their patient needed.
- NHS England should continue its commitment and work to establish its NHS Special Schools Eye Care Service, ensuring that it is sustainably funded and that it has the legislative backing it needs as a prescribed ‘additional’

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<sup>38</sup> See [fingertips.phe.org.uk/profile/atlas-of-variation](https://fingertips.phe.org.uk/profile/atlas-of-variation)

service in primary ophthalmic care.<sup>39</sup> As part of this, the SEND review should ensure that children's vision needs are recorded into their Education, Health and Care Plan.

- Similarly, NHS England should mandate Integrated Care Systems to introduce the prescribed LOCSU learning disability eye care community pathway in their areas, complementing the Special Schools Eye Care Service by providing an enhanced offer to children not attending special schools and adults with learning disabilities (including children transitioning from the special schools service).
- Commissioners may wish to consider extending this as an integrated pathway for other patients who may experience difficulties with eye care, encompassing referrals in and out of secondary care.<sup>40</sup> There is also a case for similar learning disabilities pathways to be created for Diabetic Eye Screening and follow up support.
- Reforms to ensure better access to glasses, so that people can be issued with spare pairs, and more flexible and resilient frames in case of damage. We recommend a legislative change so that dispensing of glasses to people with learning disabilities should be undertaken by a dispensing optician or optometrist rather than unregistered staff.<sup>41</sup>
- There need to be failsafe mechanisms to ensure people with learning disabilities do not 'fall through the net' when needing certification and eye care surgery and follow up treatment in the current outpatient transformation programme. This includes reinforcement of existing clinical guidelines for those patients with learning disabilities, so there are reasonable adjustments in eye care, treatment and surgery (and support from community and acute learning disability nurses).<sup>42</sup> Certification should be based on a functional vision assessment if patients cannot complete full testing, and there should be better access to systems of sight loss support (vision rehabilitation, or emotional support, for example).
- As more digital systems are put in place, they should ensure patients with learning disabilities are identified and highlighted throughout their eye care journey (whether in primary care NHS sight testing, secondary care and in screening services, such as diabetic eye screening).

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<sup>39</sup> NHS England will be able to prescribe what primary ophthalmic services are needed under the new Health and Social Care Act 2022, as will the Secretary of State for Health and Social Care.

<sup>40</sup> For example see joint statement by College of Optometrists and Royal College of Ophthalmologists [www.college-optometrists.org/news/2021/july/joint-statement-on-our-vision-for-safe-and-sustain](http://www.college-optometrists.org/news/2021/july/joint-statement-on-our-vision-for-safe-and-sustain)

<sup>41</sup> This requires a change to primary legislation: Opticians Act 1989 section 27

<sup>42</sup> For example see [Quality Standards for Services for Patients with Learning Disabilities 2014 | The Royal College of Ophthalmologists \(rcophth.ac.uk\)](http://www.rcophth.ac.uk) and College of Optometrists guidance [Examining patients with learning disabilities - College of Optometrists \(college-optometrists.org\)](http://college-optometrists.org)

- National recognition of the importance of eye care for people with learning disabilities and the high prevalence of sight problems. For example in national child health and learning disability strategies and programmes, such as the 'red book' for child health, the GP annual health check scheme and the Transforming Care Programme.
- A continued focus training and recognition of the visual needs of people with learning disabilities across health and social care, particularly for professionals such as GPs and care staff, who are often the 'gatekeepers' for health checks and treatment. This training should be led by people with learning disabilities.
- For eye care professionals, this means Health Education England providing better access to training funding for optometrists and dispensing opticians. It also means the regulator, the General Optical Council, has a role to play in helping people understand who may have experience in seeing patients with learning disabilities and a better oversight of access and experiences in domiciliary eye care.

## **Conclusion**

The health inequalities experienced by people with learning disabilities are amongst the very worst experienced by the general population. The way Covid 19 further exposed the health inequalities experienced by people with learning disabilities means reforms are even more vital. Without improving access to community and secondary care for people with learning disabilities, a commensurate increase in preventable sight loss will occur.