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A review of the evidence that people with learning disabilities experience eye health inequalities: What policies can better ensure an equal right to sight?

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Abstract

Background: People with a learning disability experience challenges accessing primary health care services, including eye care services.

Methods: Eye care needs of people with a learning disability, and how well they are met by existing services in England, were explored. Barriers and enablers to accessing these services were investigated. This was informed by a scoping review of the literature and a historic literature library.

Findings: Adults with a learning disability are 10 times more likely than other adults to have a serious sight problem and children with learning disabilities are 28 times more likely. There is good evidence of high levels of unmet eye care need special schools in England with over 4 in 10 children attending having no history of any eye care.

Conclusion: The authors discuss possible systemic changes to address these inequalities in England. These include automatic entitlement to an NHS sight test annually, specialist pathways in community opticians, eye care services in special schools, and peer to peer and peer to professional promotion of services by people with lived experience. Dedicated care pathways have improved uptake of services in other areas of primary care. Research into the effectiveness of lived experience eye health advocacy is needed.

KEYWORDS

eyes, inequalities, sight tests, spectacles, vision

Accessible summaries

- · People with learning disabilities are much more likely to have sight problems but much less likely to get the eye care they need.
- Everyone should be able to access good eye care.
- Not getting good eye care puts eyesight at risk and existing problems might not be discovered.
- We look at what helps people get better eye care and what stops people from getting it.

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- -WILEY 303 • We found that improving awareness, better staff training and good communica-• Special eye care services for people with learning disabilities have been designed but are not available in much of the UK. Having these specialist services across
- 1 INTRODUCTION

It is well established that individuals with learning disabilities have poorer health outcomes than those without learning disabilities, and the focus on improving these outcomes has often, understandably, concentrated on health issues that can cause early mortality (White et al., 2021). This paper explores the eye care needs of people with learning disabilities and whether they are accessing timely, appropriate, and effective eve care.

tion are important.

Sight loss is a growing public health issue affecting 2 million people in the UK (RNIB, 2015-2023). For the overall global population, up to half of all visual impairment can be avoided with 42% of moderate to severe avoidable visual impairment being caused by not having an appropriate spectacle correction (Steinmetz et al., 2021). Using prevalence data (Emerson & Robertson, 2011), serious sight problems are estimated to be 10 times more prevalent in the adult learning disabled population, rising to 28 times in childhood.

2 METHODOLOGY

This review is based on the combination of a historic library of resources used by SeeAbility in its campaigning work and a scoping review carried out to update this library. The historic library of articles number 285 taken from the peer reviewed and grey literature as well as government, NHS and professional body guidelines relating to learning disability health care and eye care which has been collated using a variety of undocumented and nonsystematic methodologies between 2014 and June 2023. The scoping review to source evidence of eye care inequalities experienced by people with a learning disability was first carried out in April 2023 and updated since interrogating the following databases: Embase via OVID, Emcare via OVID, Medline via OVID, Web of Science, CINAHL and SCOPUS. The following key terms were used in the scoping review: inequality, health outcomes, health inequality, intellectual disability, learning disability, sight test, general ophthalmic service, eye examination, sight impairment, vision, visual impairment, eye disease, refractive error, eye health, ophthalmology, optometry, dispensing optician. The search methodology is set out in Supporting Information: Appendix 1. In total 203 papers were identified. Fifty-seven were excluded as duplicates and 113 were excluded using the criteria set out in Table 1 (Supporting Information: Appendix 1). The scoping review produced a total of 33 papers; of these 13 were new additions to our existing library.

3 **EYE HEALTH NEEDS**

nations would help more people get the eye care they need.

Vision problems are present in 47%-50% of the learning-disabled population (Donaldson et al., 2019; Kinnear et al., 2018) with incidence rising with severity of learning disability (Warburg, 2001).

The estimated prevalence of visual impairment among adults with learning disabilities in the UK is 10 times greater than in the general population (Emerson & Robertson, 2011). 0.2% of the overall childhood population have a visual impairment which cannot be treated (Solebo et al., 2017), this rises to 14% in children with a learning disability (Das et al., 2010). A UK-wide epidemiological study evidenced that 72% of children with a visual impairment will have other clinically significant nonophthalmic impairments or conditions (Teoh et al., 2021).

People with learning disabilities are more likely than the overall population to experience a wide range of eye conditions and certain vision problems are associated with specific diagnoses such as Down's Syndrome and cerebral palsy.

At least 60% of adults with learning disability need spectacles, 44% have strabismus and cataracts, optic nerve pathology and cerebral visual impairment (CVI) are more prevalent than in the general population (McKibbin et al., 2018; van Isterdael, 2006; van Splunder et al., 2006). Approximately 40% of children attending special school need spectacles (Das et al., 2010; Donaldson et al., 2019; Pilling & Outhwaite, 2017; Woodhouse et al., 2014) and this increases to over 80% of children with Down syndrome (Al-Bagdady et al., 2011; Shapiro & France, 1985; Tomita et al., 2013). There is increasing evidence that autism spectrum disorder is associated with

 TABLE 1
 Summary of published recommendations for improving
access to primary care health services for people with learning disabilities and autism.

Good staff knowledge and skills/training
Joint working with learning disability services
Good communication between services
Specialist service delivery models which ensure sufficient time
Provision of accessible information
Promotion of services to people with a learning disability and their carers
Peer to peer and peer to professional advocacy to encourage uptake

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a higher prevalence of visual problems (Anketell et al., 2014, 2018; Behrmann et al., 2006; Croen et al., 2015; Posar & Visconti, 2017; Rydzewska et al., 2019).

Premature birth is a major risk factor for learning disability, autism and eye problems (Salt & Sargent, 2014). CVI, accounts for 48% of cases of unavoidable childhood visual impairment (Mitry et al., 2013; Teoh et al., 2021).

0.27% of the general population will develop keratoconus, a sight threatening and progressive degeneration of the cornea, this increases to around 5% of the population with Trisomy 21 (Campbell & Woodhouse, 2014). People with learning disabilities are more likely to have diabetes (Cooper et al., 2015) which raises the risk of cataract, diabetic retinopathy and glaucoma.

As people with learning disabilities grow older, they may experience the same age-related eye conditions as the rest of the population such as presbyopia (which can be corrected with bifocal or multifocal spectacles), cataracts, which if detected can be treated surgically, or sight threatening conditions such as age-related macular degeneration and glaucoma. In people with Down syndrome these age-related changes may happen up to 20 years earlier (Malt et al., 2013).

There is a known association between visual impairment and socioeconomic deprivation (McKibbin et al., 2018; Public Health England & NHS England, 2021). Given people with learning disabilities are more likely to experience poverty and disadvantage (Emerson, 2007) it can be hypothesised that this will also influence prevalence of visual impairment in this patient cohort.

People with learning disabilities may be unable to effectively communicate poor vision or a deterioration in their vision, one systematic review found a significant and independent association between visual impairment and self-injurious behaviour (de Winter et al., 2011).

There is a risk of diagnostic overshadowing with behaviours due to poor vision being attributed in error to a person's learning disability diagnosis. For example, many behaviours associated with autism overlap with those due to sight loss (Ludwig et al., 2022). People with learning disabilities may head bang, eye press or poke (Carvill, 2001), and eye rubbing may be seen in patients with eye infections or eye conditions. These all present risks of eye injury.

For people with learning disabilities who may already need help with activities of daily living, sight problems can make daily life more difficult still. Using observant-based questionnaires before expert visual function assessment, visual impairment in addition to learning disability has been shown to significantly decrease daily living skills, confidence, mobility, and communication and language (Evenhuis et al., 2009).

4 | NATIONAL EYE HEALTH POLICY

There is currently no National Eye Health Strategy in England, although one has been proposed (National Eye Health Strategy Bill, 2023) which would provide policies to address inequalities and prevent sight loss. A national public health reporting framework has been established to understand number of people being certified for sight loss (Gov.uk, 2022). A recent government and NHS policy Eye Health Atlas of Variation resource and data tool aims to address sight loss and the variation in services, through local health planning and better use of primary care (Public Health England & NHS England, 2021) This includes a chapter on learning disability, key recommendations of which include commissioning of specialist community and hospital eye care pathways, more widespread use of functional vision assessment, including to certify visual impairment, and better data collection.

There are also consensus reports and recommendations on monitoring of at risk groups, these include children born premature or with cerebral palsy and children with neurodevelopmental impairments, including Down syndrome (Alan Emond, 2019; Royal College of Ophthalmologists, 2021). Except for protocols for retinopathy of prematurity screening, there are a lack of mandated national programmes.

5 | EXISTING EYE CARE SERVICES

5.1 | General ophthalmic service (GOS)

Eligible groups can get their eyes and vision checked through the NHS or through a private sight test at a community optical practice with a registered optometrist. Eligibility for an NHS GOS sight test in the UK is by age, benefits received or risk factors, except in Scotland where the entire population is eligible. People with learning disability are not listed as an at-risk group. This means some people with learning disabilities will find themselves having to pay privately for a sight test. Sight tests include a 'refraction' which will evaluate the need for spectacles, which can be done using entirely objective measurements of the eyes as well as subjective choices. A sight test will also detect abnormality or disease in the eye and assess visual function (NHS England, 2008).

In England, optical practices are paid a fee for each completed NHS sight test (at June 2023 £23.14) (Department for Health and Social Care, 2023). There is additional provision for mobile sight tests in a person's home (including residential care) or a day centre if that person is unable to leave home unaccompanied. The NHS sight test fees do not cover the actual cost (Shickle, Todkill, et al., 2015). As a hybrid model, this means private patients and the purchasing of eyewear cross-subsidises NHS care. This creates a public perception that opticians are 'retailers' more than a place which provides clinical care (Hayden et al., 2012). Significantly, it also builds in disincentives to see patients who require additional time (General Optical Council, 2022; Public Health England, 2020) This has caused some to state that the contract itself is contrary to the public health interest (Shickle, Davey, et al., 2015).

There is a system of eligibility for NHS vouchers towards the cost of spectacles, again learning disability is not a criteria. Dispensing opticians are regulated professionals qualified in dispensing spectacles, and in some cases, contact lenses and low vision aids. However, only children and people registered with a visual impairment are required to have their spectacles supplied by a registered professional.

5.2 | Additional primary eye care pathways

In addition to GOS, optical practices may deliver any of a range of locally commissioned extended primary eye care services, for which they receive additional training and funding. These include referral refinement for minor eye conditions, cataracts, suspect glaucoma, children failing school vision screening and Easy Eye Care for people with a learning disability and autistic people (LOCSU, 2020). These services are commissioned at Integrated Care System level to reduce volume of referral from the GOS into secondary care and to best utilise the skills of the primary eve care workforce. Providers of the Easy Eye Care pathway provide longer and/or multiple appointments and specially adapted assessments with recommended referral criteria (Pilling et al., 2022). At June 2023 it is commissioned for only around 5% of the learning disabled population. In the authors experience, it can be difficult to engage Integrated Care System commissioners to establish any of these pathways and the Easy Care Pathway is relatively low volume and so does not address hospital waiting lists as dramatically as the other additional primary eye care pathways and so is not prioritised.

5.3 | Special schools eye care

In 2017 Public Health England guidelines concluded that school entry vision screening is not suitable for children attending special schools (Public Health England, 2019) and recommended a model of care providing an in school sight test, spectacles if needed and a report on the child's visual abilities that could be used in the child's support plan (The Royal College of Ophthalmologists, 2016). This was based on the evidence of various service models and research studies (Little & Saunders, 2015; Pilling & Outhwaite, 2017; Woodhouse et al., 2014). These studies showed that at least 40% of the special school population had no eye care history, despite half having a significant visual problem. Parents report a strong preference for this in-school model, finding it easier to access and less stressful than having to access opticians or hospital services (Donaldson et al., 2018).

This model initially began to be tested by the NHS in 2021, after a commitment in the NHS Long Term Plan (Cheater, 2019) to improve eye care for children with learning disabilities. It is a multidisciplinary service, bolstering any pre-existing services in special schools, and providing eye care where there has been none previously (Allen et al., 2021). In 2023 the government and NHS England committed to rollout a programme of sight testing for children in all special schools (Department of Health and Social Care, 2023).

5.4 | Hospital eye service

People may receive eye care in secondary care and in some areas outreach services may be provided in schools or other settings. Spectacles or other aids may be dispensed at hospital, or, more commonly, a prescription or voucher is supplied for spectacles to be obtained from a community optical practice.

Outpatient eye clinics are currently struggling to meet demand (NHS England, 2022). At the start of 2023, 630,000 people were on the outpatient ophthalmology waiting list (NHS England, 2023). Delays to treatment may be sight threatening (Foot & MacEwen, 2017) and people with learning disabilities are more likely to rely on hospital services as well being more at risk of missing or experiencing incomplete appointments (Ramsey et al., 2022) leading to further delay.

5.5 | Other eye care services

Government recommendations are for school entry vision screen at ages 4–5 years for children not attending special school (Public Health England, 2019). There is evidence that this does not detect all childhood vision problems (O'Donoghue et al., 2012).

The NHS Diabetic Eye Screening Programme (Public Health England, 2021) for diabetic retinopathy if for anyone diagnosed with diabetes and aged 12 or over providing annual screening for diabetic retinopathy. This does not replace the need for a sight test.

All people with learning disabilities aged 14 or over should receive a GP Annual health check. (Public Health England, 2016). Templates in use include a specific prompt on vision. GPs are not registered to perform sight tests, cannot prescribe spectacles, and do not have the equipment necessary to detect much eye disease, although they are often the first port of call for people worried about an eye problem (General Optical Council, 2023).

This is a summary of UK eye care services, but there will be many other surveillance, referral, and support mechanisms in use among professionals as diverse as ophthalmologists, orthoptists, paediatricians and geriatricians, through to school nurses, health visitors, learning disability nurses and vision rehabilitation workers.

6 | EFFECTIVENESS OF EXISTING SERVICES

Systematic reviews have mapped the evidence on entry access to primary and community healthcare services for this patient population, and conceptual frameworks have been used to describe barriers and enablers for different healthcare interventions (Alborz et al., 2005; Cantrell et al., 2020; Hanlon et al., 2018; Shea et al., 2022; Ummer-Christian et al., 2018). None of these focus on eye care services, however. They all identify underutilisation of primary care services despite higher prevalence of need than in the general population. WILEY-

People with learning disabilities have a mean of 11.04 co-morbidities (Henderson et al., 2007). A UK-wide epidemiological study evidenced that 72% of children with a visual impairment will have other clinically significant nonophthalmic impairments or conditions (Teoh et al., 2021). With such high levels of healthcare need, access to routine primary eye care, in the absence of obvious signs, symptoms or public health messaging, is unlikely to be prioritised. Multiple healthcare needs may make attending eye care appointments challenging. Among children with learning disabilities, one report found a 54.8% nonattendance rate at a hospital eye clinic (Jmor et al., 2014).

Access to primary eye care is often symptom-led (Leamon et al., 2014). However, most irreversible sight loss is pain free and insidious and so routine eye care is recommended. The perceived 'retail' nature of optical care and concerns about cost may be a barrier (Leamon et al., 2014). There are also misconceptions around sight testing itself, for example, that it is only possible if a person is verbal or literate. The low fee for a GOS sight test is a disincentive to providers to promote GOS eye care to a group for whom it is likely to not be cost-effective owing to a likely need for longer 'chair time'. This is also likely to lead to referrals into hospital which could have be managed in primary care, and resulting increased costs.

There is a national sight testing data set, but it does not flag this population and so levels of use of the GOS sight test system is unknown. There is evidence that the adult learning-disabled population are often missing out on eye care (Woodhouse et al., 2000, 2004). One report found that only 44% of people with a learning disability identified they had been for a sight test within 2 years (Healthwatch, 2020). In one study of adults attending a day centre (N = 147), around 70% were likely to benefit from spectacles but only 20% actually had them (Woodhouse et al., 2000) while in another telephone survey of people with learning disabilities, only 43% of those previously prescribed spectacles reported successfully wearing them, something the authors attributed to lack of follow up support (Starling et al., 2006). A German study found only 38.9% of workers with learning disability reported an eye test in the past 3 years and 6.7% had never received eye care (n = 224). (Eisenbarth, 2018) In the same study, 36.2% of participants needed new or changed spectacles.

The majority of children with profound and multiple learning disabilities in the UK attend special schools and studies from this population provide some of the most robust eye care need prevalence data (Black et al., 2019; Das et al., 2010; Donaldson et al., 2019; Little & Saunders, 2015; Pilling & Outhwaite, 2017; Woodhouse et al., 2014). These studies also evidence that many children with learning disabilities could have benefitted from eye care interventions much earlier to support general and visual development. At least 40% had no parental reported eye care history (from either hospital or opticians) with only around 10% ever having accessed a high street optician by the age of 11. Up to 53% of pupils needed spectacles, but only around 30% had previously had them prescribed. These studies evidence that around half of the special school population have a significant visual problem and there is much unmet need, including up to 10%

of students with unidentified poor vision sufficient to qualify for registration as visually impaired.

As already stated, rates of diabetes are higher in the population with learning disabilities but there is evidence that diabetic eye screening is failing to provide an adequate monitoring system for the learning disabled population (Pilling, 2015). Audits of the GP annual health check have found vision status is often not raised or recorded (ranges of 44.1%–52.8% (Buszewicz et al., 2014; Carey et al., 2017)).

It is important that individuals and their supporters understand their visual abilities, needs and limitations, so that they can be supported optimally and strategies, such as if and how spectacles should be used, ensuring optimal positioning and size of visual targets through to mobility training can be put in place. This is unlikely to be provided from a GOS sight test as the only contractual requirement is to provide a copy of any spectacle prescription (legislation.gov.uk, 2008). Even if this information is available, there is evidence that it is not making its way into the appropriate support plans (Little & Saunders, 2015). There is a published register on sight loss held by councils in England, which includes the voluntary opportunity to record if the person has a learning disability. While not definitive, it helps demonstrate the likelihood that sight loss is greatly underreported. In 2021 only 5775 people with learning disabilities were on the register (NHS Digital, 2021), much less than the 130,124 people with a learning disability (Emerson & Robertson, 2011) estimated to be meet the criteria for sight loss registration.

7 | HOW CAN ACCESS TO EYE CARE SERVICES BE IMPROVED?

The introduction of the annual health check in general practice and national provisions for special care dentistry are acknowledged as helpful in raising awareness with people with learning disabilities, carers and learning disability nurses.

Table 1 summarises recommendations taken from reviews we identified exploring access to primary care for people with a learning disability (Alborz et al., 2005; Cantrell et al., 2020; Hanlon et al., 2018; Shea et al., 2022; Ummer-Christian et al., 2018).

Accessibility can be enhanced by good support and reasonable adjustments as required under the Equality Act (HM Government, 2010). In 2020 Public Health England published a 'guide to reasonable adjustments in eye care' (Public Health England, 2020) which provides recommendations specific to eye care which align with many findings of the review papers referenced above.

There are many adapted ways of assessing vision (such as using picture charts, the Bradford Function Box (Pilling et al., 2016), grating acuity tests, including 'game-based' applications such as the Peekaboo iPad application (Livingstone et al., 2019) and objective assessment (Donaldson, 2017) that will enable visual status to be assessed and spectacles prescribed when needed. However finding an optometrist with the confidence, time and skills to provide the full and necessary support a patient with moderate to severe learning disabilities will need has been reported to be a struggle by carers/

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supporters (Healthwatch, 2020). This leads to people finding themselves receiving what should be routine primary eye care in the hospital secondary care system. There also appears to be low awareness of the possibility of home visits among many disabled people (Shah et al., 2015). Attempts have been made to address practical concerns with the optical contract. NHS England has recently clarified that practitioners can still claim the sight test fee if they have made reasonable attempts to undertake the test on a 'clinically challenging' patient (NHS England, 2019).

Awareness training in learning disability and autism across health and social care delivered by self-advocates is now mandated for all Care Quality Commission regulated health and social care providers (Health Education England, 2022). So far this has not been mandated for optical practice staff. Vision awareness training among carers, supporters, and care professionals can also help address misconceptions, raise uptake of eye care and spectacle use and action appropriate modifications for people's visual impairment (Dick et al., 2015). Tools that enable these third parties to assess how a person is functionally using their vision (SeeAbility, n.d.-a) are helpful in building understanding (Li et al., 2015).

There are recommendations that people with lived experience should be involved whenever possible in service development (Sunkel & Sartor, 2022). SeeAbility employ 'eye care champions' (SeeAbility, n.d.-b) with lived experience of learning disability who promote 'eye care awareness' among people with learning disabilities, their supporters and other health care professionals. They make use of a wide range of resources, including in easy read, (SeeAbility, 2020) films and wordless books to provide information and support.

The high prevalence of eye problems and the low uptake of primary eyecare and primary health care in general documented in this review leads us to the assumption that public awareness of the need for regular eye care for this patient group is low. Unlike other targeted clinical at-risk groups such as people with diabetes or glaucoma. Learning disability is not a specific eligibility criteria for an NHS sight test (NHS England, 2008). Even though the risk of sight problems is higher for this group this omission fails to highlight the need for regular eyecare to both the public and professional staff and is a likely contributor to low uptake of services and poor long-term outcomes.

Eligibility rules for access to NHS funded spectacles and 'spares and repairs' of spectacles are also particularly complex (legislation. gov.uk, 2008). The NHS voucher for spectacles only allows one pair, so those who regularly break their spectacles are often left without while they wait for a case to be made for a replacement under the NHS scheme. Legislation specifies that certain high-risk groups such as children and those with sight impairment can only have optical appliances fitted by a qualified dispensing optician but people with a learning disability are not included in this protection. This omission means that even though there is a much higher prevalence of sensory issues, high refractive error, wheelchair headrest use and complex visual needs such as communication technology, which all make the successful supply of optimal spectacle correction considerably more complex, many people within these groups will have their spectacles supplied and fitted by unregulated individuals with no, or minimal, training. Anecdotal experience of the authors in clinical practice suggests that this leads to poorly fitting spectacles, failure to adapt to wear and hence poor compliance with consequently poor long-term outcomes.

8 | CONCLUSIONS AND RECOMMENDATIONS

This review brings together the evidence that shows people with learning disabilities of all ages have a high prevalence of eye problems and are not accessing primary eyecare services that they need. This results in avoidable and/or undiagnosed visual impairment in the learning-disabled population.

Learning disability is not an entitled characteristic for existing NHS funded primary eyecare through the GOS system. Unlike other high-risk groups, people with learning disability can have their spectacles fitted by any nonregulated supplier even though successful supply of optimal spectacle correction is considerably more complex.

Evidence exists that uptake of services improves where national schemes and pathways are in place in the form of annual health checks and special needs dentistry contracts. Despite the presence of these national schemes in other areas of primary care, there is a lack of similar focus on targeted eyecare provision. It can be hypothesised then that reliance on local initiatives and reasonable adjustments will not address the eye care inequalities this review evidence.

Peer to peer and peer to professional lived experience advocacy has been proposed (Cantrell et al., 2020) and is being used to try and improve uptake and commissioning of services (SeeAbility, n.d.-b) although evidence base for its effectiveness has not yet been established.

The authors recommend:

- Policy change so that all people with learning disabilities are entitled to an annual NHS funded sight test. This would align with the GP learning disability annual health check and send a clear public health message of the increased risk of sight problems in this patient population. It would also allow for data to be collected.
- The identification of people with learning disabilities as a vulnerable group who should have spectacles supplied only by a registered professional, as is already the case for all children and people registered as sight impaired (Gov.uk, 1989).
- A special school eye care services across England to the Framework model recommended by the eye care professional bodies (The Royal College of Ophthalmologists, 2016)
- The mandated commissioning of a community eye care pathway for people with learning disabilities (LOCSU, 2020) in each Integrated Care System in England, with supported promotion by self-advocates and commissioners.

These are schemes which could potentially benefit or be adopted for other 'complex' patient groups such as those with dementia (Shah et al., 2015) and brain injury and in other settings, and in so doing address other eye health inequalities.

9 | LIMITATIONS OF THIS PAPER

Publication bias may exist due to the mixed method review strategy. We did not identify publications reporting on barriers and enablers to eye care as reported by people with a learning disability. Cost effectiveness of timely intervention was not explored. Our discussion confines itself to the situation for community optical care in England, rather than the rest of the UK where some optical care improvements have been made. For example, sight tests are free to all in Scotland, and optometrists are paid an additional fee to see patients with complex needs. The paper provides a general overview of the current situation regarding eye care access for people with learning disabilities in England but more understanding of the experiences of different cohorts of patients with learning disabilities is needed. This should include people with learning disability from minority ethnic populations, older people and those who use mobile domiciliary services and hospital eye care.

DATA AVAILABILITY STATEMENT

Data sharing not applicable to this article as no datasets were generated or analysed during the current study.

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Additional supporting information can be found online in the Supporting Information section at the end of this article.

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