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Citation: Donaldson, L. A. (2026). Evidencing and addressing inequalities in access to eye care for two high risk groups: very young children and people with learning disabilities. (Unpublished Doctoral thesis, City St George's, University of London)

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**Evidencing and addressing inequalities in access to
eye care for two high-risk groups: children under six
and people with learning disabilities**

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A thesis submitted in partial fulfilment of the requirements for degree of
Doctor of Philosophy in optometry
School of Health and Medical Sciences
City St George's, University of London

March 2026

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List of publications submitted

Donaldson, L.A., Patel, M, O' Brien, D and Karas M. (2025). Parental satisfaction with a special schools eyecare and spectacle dispensing service. *British Journal of Visual Impairment*.
<http://dx.doi.org/10.1177/02646196251382450>

Donaldson, L., O'Brien, D., & Karas, M. (2024). A review of the evidence that people with learning disabilities experience eye health inequalities: What policies can better ensure an equal right to sight? *British Journal of Learning Disabilities*, 52(2). <https://doi.org/10.1111/bld.12573>

Karas, M., O'Brien, D., Campbell, L., Lunness, R., Kennedy, J., McGill, G., Kill, S., & **Donaldson, L.** (2024). The role of lived experience eye care champions in improving awareness and access to eye care services for people with learning disabilities and/or autism. *British Journal of Learning Disabilities*. <https://doi.org/10.1111/bld.12594>

Pilling, R. F., **Donaldson, L.**, Karas, M., *et al.* (2022). Referral thresholds for an integrated learning disability eye care pathway: A consensus approach. *Eye*, 36, 742–748. <https://doi.org/10.1038/s41433-021-01516-y>.

Donaldson, L.¹, & Karas, M. (2020). Optometric care of children with significant learning disabilities. *Optometry in Practice*. <https://www.college-optometrists.org/professional-development/college-journals/optometry-in-practice/all-oip-articles/volume-21,-issue-3/2020-09-optometriccareofchildrenwithsignificantlea>

Donaldson, L. A., Karas, M., O'Brien, D., & Woodhouse, J. M. (2019). Findings from an opt-in eye examination service in English special schools: Is vision screening effective for this population? *PLOS ONE*, 14(3), e0212733. <https://doi.org/10.1371/journal.pone.0212733>

¹ There is some disparity in nomenclature across papers. To confirm Donaldson, L.A., Donaldson, L. and Lisa Donaldson all refer to Donaldson L.A.

Donaldson, L. A., Subramanian, A., & Conway, M. L. (2018). Eye care in young children: A parent survey exploring access and barriers. *Clinical and Experimental Optometry*, 101(4), 521–526.
<https://doi.org/10.1111/cxo.12683>

SeeAbility (lead **Lisa Donaldson**), Framework group. Framework for provision of eye care in special schools in England (2016). <https://www.rcophth.ac.uk/resources-listing/framework-for-provision-of-eye-care-in-special-schools-in-england/>

Donaldson, L. A., Karas, M. P., Charles, A. E., & Adams, G. G. W. (2002). Paediatric community vision screening with combined optometric and orthoptic care: A 64-month review. *Ophthalmic and Physiological Optics*, 22, 26–31. <https://doi.org/10.1046/j.1475-1313.2002.00001.x>

Karas, M. P., **Donaldson, L. A.**, Charles, A., Silver, J., Hodes, D., & Adams, G. G. W. (1999). Paediatric community vision screening—a new model. *Ophthalmic and Physiological Optics*.
<https://doi.org/10.1046/j.1475-1313.1999.00425.x>

Co-author Statement of Contributions

Publication	Statement of contributions	Co-author signatures confirming accuracy of statement of contribution
Donaldson, L.A. , Patel, M, O' Brien, D and Karas M. (2025). Parental satisfaction with a special schools eyecare and spectacle dispensing service. <i>British Journal of Visual Impairment</i> . http://dx.doi.org/10.1177/02646196251382450	LD, MK - conceptualization, methodology LD, MP - project administration LD, MK and MP - formal analysis LD writing original draft LD, MK, DO'B - writing review and editing	Malvi Patel (MP) Donna O'Brien (DO'B) Marek Karas (MK)
Donaldson, L. , O'Brien, D., & Karas, M. (2024). A review of the evidence that people with learning disabilities experience eye health inequalities: What policies can better ensure an equal right to sight? <i>British Journal of Learning Disabilities</i> , 52(2). https://doi.org/10.1111/bld.12573	LD, DO'B conceptualization LD, MK methodology LD project administration LD writing – original draft LD, MK, DO'B writing - review and editing	Donna O'Brien (DO'B) Marek Karas (MK)
Karas, M., O'Brien, D., Campbell, L., Lunness, R., Kennedy, J., McGill, G., Kill, S., & Donaldson, L. (2024). The role of lived experience eye care champions in improving awareness and access to eye care services for people with learning disabilities and/or autism. <i>British Journal of Learning Disabilities</i> . https://doi.org/10.1111/bld.12594	LD, MK and DO'B - conceptualisation and funding acquisition LD and MK - investigation and methodology MK writing original draft LD, MK, DO'B, LC, GMcG, RL, JK, SK Writing review and editing	Marek Karas Donna O'Brien Lance Campbell (LC) Rebecca Lunness (RL) Joanne Kennedy (JK) Grace McGill (GMcG) Stephen Kill (SK)
Pilling, R. F., Donaldson, L. , Karas, M., Leitch, R.J., Bunting, H., Naru, R., Ilett, G. (2022). Referral thresholds for an integrated learning disability eye care pathway: A consensus approach. <i>Eye</i> , 36, 742–748. https://doi.org/10.1038/s41433-021-01516-y .	LD, RP and MK - conceptualisation RP investigation, methodology, project administration, writing original draft. LD, MK, RP writing review and editing	Rachel Pilling (RP) Marek Karas

Donaldson, L., & Karas, M. (2020). Optometric care of children with significant learning disabilities. <i>Optometry in Practice</i>. https://www.college-optometrists.org/professional-development/college-journals/optometry-in-practice/all-oip-articles/volume-21,-issue-3/2020-09-optometriccareofchildrenwithsignificantlea	LD conceptualisation, investigation, project administration, writing original draft LD and MK writing review and editing	Marek Karas
Donaldson, L. A., Karas, M., O'Brien, D., & Woodhouse, J. M. (2019). Findings from an opt-in eye examination service in English special schools: Is vision screening effective for this population? <i>PLOS ONE</i>, 14(3), e0212733. https://doi.org/10.1371/journal.pone.0212733	JMW, MK, DO'B, LD conceptualisation, JMW supervision, JMW, MK and LD methodology, LD writing original draft, LD, MK, DO'B, JMW, writing review and editing	Marek Karas Donna O'Brien J Margaret Woodhouse (JMW)
Donaldson, L. A., Subramanian, A., & Conway, M. L. (2018). Eye care in young children: A parent survey exploring access and barriers. <i>Clinical and Experimental Optometry</i>, 101(4), 521–526. https://doi.org/10.1111/cxo.12683	LD, MC, AS conceptualisation, funding acquisition, methodology LD investigation, project administration MC, AS supervision LD writing original draft LD, MC, AS writing-review and editing	Miriam Conway Ahalya Subramanian
SeeAbility (lead Lisa Donaldson), Framework group. Framework for provision of eye care in special schools in England (2016). https://www.rcophth.ac.uk/resources-listing/framework-for-provision-of-eye-care-in-special-schools-in-england/	DO'B, LD conceptualisation LD & DO'B writing original draft and review and editing	Donna O'Brien
Donaldson, L. A., Karas, M. P., Charles, A. E., & Adams, G. G. W. (2002). Paediatric community vision screening with combined optometric and	MK, LD conceptualisation, methodology, investigation, project	Marek Karas

orthoptic care: A 64-month review. <i>Ophthalmic and Physiological Optics</i>, 22, 26–31. https://doi.org/10.1046/j.1475-1313.2002.00001.x	administration, writing original draft, review and editing	
Karas, M. P., Donaldson, L. A., Charles, A., Silver, J., Hodes, D., & Adams, G. G. W. (1999). Paediatric community vision screening—a new model. <i>Ophthalmic and Physiological Optics</i>. https://doi.org/10.1046/j.1475-1313.1999.00425.x	MK project administration, writing original draft LD, MK investigation, methodology, writing-review and editing	Marek Karas

Acknowledgements

I am sincerely grateful for the unwavering support of my supervisors Dr. Ahalya Subramanian and Dr. Miriam Conway. They have both given freely of their extensive knowledge and expertise and been a huge source of inspiration and encouragement, patiently guiding me through the process of completing this thesis. I must also thank them as co-authors, nurturing my research abilities and giving me the confidence and guidance to continue my research.

Special thanks to my other co-authors, Marek Karas for his strong encouragement and support from our very first joint publication in 1999, Donna O'Brien for her dedication in disseminating our joint work and Prof Rachel Pilling and Prof Maggie Woodhouse for inspiring me and believing in me.

I would also like to extend my heartfelt thanks to the SeeAbility trustees and senior leadership team, especially Lisa Hopkins CEO for believing in this work and being steadfastly supportive of it. Support from SeeAbility has enabled much of my research.

I am grateful to City St George's, University of London for supporting me in the registration and submission of this thesis.

Finally, thank you to my wonderful family for their encouragement and support.

Abstract

This thesis by prior publication presents a coherent body of research undertaken over the past 25 years, addressing longstanding inequalities in access to eye care for two underserved populations: children under the age of six, and individuals of all ages with learning disabilities. Both groups are disproportionately disadvantaged in accessing eye care services; in part due to reduced ability to communicate visual symptoms and because eye care provision remains largely symptom-led.

The thesis draws together a series of publications, grouped under five thematic areas:

Identifying barriers to accessing eye care for young children.

Reducing the burden on secondary paediatric ophthalmology services.

Developing and evaluating specialist, targeted eye care pathways for individuals with learning disabilities.

Exploring models of advocacy, pathway promotion and satisfaction among people with learning disabilities and their families/carers.

Investigating cross-sector models of healthcare delivery to identify transferable insights for eye care services supporting people with learning disabilities.

Collectively, these works advance an applied research agenda aimed at generating evidence for policy change in the United Kingdom. The overarching goal has been to inform the development of inclusive, needs-led eye care services that address systemic access barriers and promote equitable outcomes for vulnerable populations.

Background: prevalence and impact of visual impairment

Uncorrected refractive error (which can be corrected with spectacles) is the leading cause of childhood visual impairment worldwide (Vision Loss Expert Group of the Global Burden of Disease Study; GBD 2019 Blindness and Vision Impairment Collaborators, 2024). Avoidable visual impairment may also be due to untreated amblyopia, cataract or other untreated ocular pathologies.

In the UK at 4-5 years of age, the prevalence of uncorrected refractive error significant enough to result in a presenting bilateral visual impairment is around 6% (Bruce *et al.*, 2018c). By adulthood, refractive error (exclusive of presbyopia) is present in an estimated 54% of the overall UK population (Williams *et al.*, 2015). Amblyopia has been evidenced to affect 1.36% of the global population and 2.66% of the European population (Hu *et al.*, 2022).

Visual impairment can have a significant negative impact on quality of life for both children and adults, as well as on social, emotional and educational development. The impact is more severe when it is not identified (Tseng *et al.*, 2018; Robertson *et al.*, 2022; Purola *et al.*, 2023). Therefore, timely identification of visual impairment and addressing avoidable visual impairment - whether by prescribing glasses, amblyopia therapy or medical management of cataract or eye disease - is vital for everyone. Even if visual impairment is unavoidable, outcomes for children are better if it is identified early (McConnell *et al.*, 2019). It is therefore vital for all concerned: children, their families, carers and teachers to be aware of its impact. Seventy-two percent of children diagnosed with a visual impairment have other clinically significant non-ophthalmic impairments or conditions (Teoh *et al.*, 2021).

Previous studies in Scotland (Das *et al.*, 2010), England (Pilling & Outhwaite, 2017) and Wales (Woodhouse *et al.*, 2014) have evidenced significant levels of unmet need in the special school population, a group of children known to have the most significant learning disabilities. When these studies were published, the only national guidance on eye care pathways for all children was the school entry vision screening guidelines (Public Health England, 2023) which at that time recommended routine monocular letter-based vision screening at school entry age; there was no guidance for onward referral pathways for children who failed or were unable to complete the screening. Das *et al.* (2010) found 42% of special school students required refractive correction.

Woodhouse et al. (2014) found this figure to be 50%. Pilling and Outhwaite (2017) identified children with no previous eye care history and found 33% of these children (n=157) had visual impairment as defined by the World Health Organisation (World Health Organisation, 2019). A study in Denmark evidenced a correlation between severity of learning disability and incidence of visual impairment (Nielsen *et al.*, 2007).

Adults with learning disabilities are ten times more likely to experience visual impairment than the general population (Emerson & Robertson, 2011). Published evidence of the visual requirements of this population showed high levels of demand, often unmet. Much of this published evidence of unmet need has represented people who have self-referred for care or has come from screening of athletes with mild learning disability (Woodhouse, Griffiths & Gedling, 2000; Woodhouse, Adler & Duignan, 2003, 2004). The eye care needs of adults with moderate to severe learning disabilities are not well evidenced. A large prevalence study in the Netherlands (van Splunder *et al.*, 2004) recommends '*All persons with severe or profound intellectual disabilities, and all older adults with Down's syndrome, should be considered visually impaired until proved otherwise*' due to the high incidence of previously unidentified visual impairment.

Despite over two million people in the UK living with sight loss that affects daily functioning, fewer than one in five are formally certified through the Certification of Sight Impairment (CVI) system, highlighting substantial under-registration in the general population (Royal National Institute of Blind People, 2025). People with learning disabilities have a markedly higher prevalence of visual impairment at around 30-40% (Emerson *et al.*, 2012). However, in 2022-23 in England, 6,130 people with a learning disability were recorded on the sight-loss register as either sight impaired or severely sight impaired (NHS Digital, 2024). When set against an estimated 1.3–1.5 million people with a learning disability in England (Emerson *et al.*, 2012), this represents well under 1% of the learning-disabled population indicating profound under-certification and under-recognition within current systems.

This thesis presents a body of research produced over the past 25 years, focusing on improving access to eye care for two vulnerable groups: very young children and people of all ages with learning disabilities. The research identifies barriers to eye care access for young children and explores ways to meet their needs while reducing the burden on secondary care ophthalmology clinics. This leads to the development and evaluation of specialist, targeted eye care pathways for both young children and individuals with learning disabilities.

The thesis also explores models of advocacy, pathway promotion, and satisfaction among people with learning disabilities and their families/carers. Additionally, it investigates cross-sector models of healthcare delivery to identify insights that can be transferred to eye care services supporting people with learning disabilities.

Theme 1: Identifying barriers to accessing eye care for young children

Background: What are the touchpoints for eye care for young children in England?

Newborn health check: In the UK, screening to identify visual problems is usually conducted by a medical general practitioner (GP) on all newborn babies at 6-8 weeks (*NHS Eye tests in Children*, 2023). This is part of a 'newborn health check, 'eyes, heart, hips and testes' (Gov.UK. Office for health disparities, 2025). This is intended to identify causes of the most severe visual impairments, retinoblastoma and cataract by checking for a red pupil reflex in each eye as well as for any significant structural ocular abnormalities (Rahi et al., 2010; Jullien, 2021).

School entry vision screening: In England since 2013, this has been the responsibility of local authorities as part of the 'Healthy Child' programme, taking place in school (prior to this National Health Service (NHS) Clinical Commissioning Groups (CCGs) were responsible for commissioning the service and some of these remain (now under the local NHS integrated commissioning boards (ICBs)). The National Screening Committee (NSC)'s recommended standard for assessment has been a monocular distance logMAR assessment using a letter based crowded optotype at age 4-5 years to detect amblyopia. Scotland has a nationally commissioned and standardised programme "See4School" (Public Health Scotland, 2023) defined by universal pre-school orthoptic screening, a nationally defined pathway and dataset and significantly less geographical variation. Wales and Northern Ireland have nationally mandated and standardised orthoptic-led school entry vision screening services (Public Health Agency Northern Ireland, 2020; Gov.Wales, 2024) .

Screening is also likely to identify reduced vision due to binocular refractive error (Pentland & Conway, 2024). National guidelines for this have been provided by former Public Health England (now Gov.UK); an 'orthoptic led' 'opt-in or opt-out' service is recommended with a nationally recommended service specification.

A 2012 paper (Solebo *et al.*, 2012) recommended standardising the age of vision screening as it has historically been provided at various ages including nursery (age 3 to 4) and secondary school entry (age 10 to 11). In England, Wales and Northern Ireland, this takes place in the reception year of school at age 4-5.

Pathways of care following failed vision screening have historically varied between geographical areas, with some areas seeing all children referred into a hospital paediatric eye clinic whilst in others there is no established pathway and only signposting to community opticians/optometrists. Until 2017, the national school entry vision screening guidance provided no recommended onward referral pathway for children failing or unable to access the screening test. The Clinical Council for Eye Health Commissioning recommended a commissioned pathway following failed vision screening in 2022 (Clinical council for eye health commissioning, 2022) and in 2023, the Royal College of Ophthalmologists published a recommended diagnostic pathway following failed vision screening (Royal College of Ophthalmologists, 2023).

General Ophthalmic Service (GOS) Sight Test: In England, the General Ophthalmic Service National Health Service sight test is available for free to all children under 16 and those under 19 in full time education (NHS Eye tests in Children, 2023). Children are also eligible for a voucher towards the cost of spectacles or contact lenses. If they are a ‘contractor’ or ‘performer’ under an NHS General Ophthalmic Services contract, an optometrist ‘must provide services [*a sight test*]...to an eligible person if the request is made...’ (legislation.gov.uk, 2008).

Hospital eye clinics/ orthoptic departments: In England children access these services via referral from either their general practitioner, from an NHS GOS sight test or when they fail or cannot complete school entry vision screening. All these referrals may, depending on local protocols, be made directly or via a single point of access referral management service. Children can also be referred to paediatric ophthalmology services by other community or hospital-based paediatric clinics. A 2023 review of referral accuracy for UK optometrists (Carmichael *et al.*, 2023) found only one paper looking at referrals into secondary care from optometrists for the paediatric population and this was for a small number (n=45). This paper showed 88.9% of referrals from optometrists and 66% from GPs at least partially matched the final diagnosis.

What is the evidence of barriers to accessing these services?

Newborn health screening for the most severe visual impairments has excellent coverage of over 95% (Gov.UK, 2023).

In 2025 access to school entry vision screening in England remains fragmented and inconsistent, depending on location, with only 52% of local authorities providing a school entry vision screening service that fully complies with the National Screening Committee guidelines and 11% having no provision in place at all (British and Irish Orthoptic Society, 2024). In 2025, school entry vision screening remains only recommended, not mandated, as a service to be provided by local authorities and coverage has been incomplete, frequently not including special schools. An estimated 75,000 reception-aged children in England miss vision screening each year because their local authority does not commission a service. Crucially this figure does not include children absent on screening day, children in alternative education settings including special schools and independent schools and children in areas with poorly functioning services or weak uptake monitoring (Allen, Dillon and Bowen, 2021). Currently, it cannot be determined to what extent the Royal College of Ophthalmologists' guidelines for post-vision screening pathways are being implemented in England.

Although all children are eligible to access a GOS NHS sight test, a 2021 study analysing every NHS GOS sight test in one county in England (Essex) found the average age to access a first NHS sight test was over 6.5 years (Swystun and Davey, 2021). This is clearly significantly later than ideal to avoid permanent visual loss due to amblyopia (Tailor et al., 2017) as well as delaying social, emotional and behavioural development for children with undiagnosed visual impairment (Keil et al., 2017). From a wider public health perspective, early detection and management of amblyopia, high hyperopia and myopia are likely to have significant cost-benefits over the lifetimes of those affected (Little *et al.*, 2025).

Despite being eligible to receive a GOS sight test at any age, children may be unable to access this right. In a 'mystery shopping' study (Shah, Evans and Edgar, 2007) less than half of the 100 optometrists contacted were willing to see a 1-year-old child where there were concerns of a problem with their eyes. In a 2021 study, 85% of 400 practices contacted specified a minimum age at which they would examine a child (Wilson *et al.*, 2021). A 2025 survey of 1008 Mumsnet users (Mumsnet, 2025) evidenced parental confusion concerning eye care services and when, how and where they can be accessed, with 21% of parents believing a school vision screening test is the same as an eye test at an optician (optometrist).

As with all areas of clinical practice, there is a need for clinicians to have sufficient training and regular experience. Only three institutions offer the College of Optometrists' higher qualification in paediatric eye care (College of Optometrists, 2025), whereas, by contrast, nine institutions provide professional certificates in glaucoma. Examining young children often requires additional time to build a rapport and develop trust, as well as possible multiple visits and the use of cycloplegic eye drops to achieve an accurate refractive result. Children are unlikely to report visual symptoms, especially if these are longstanding (Pentland & Conway, 2024) and hence this is not likely to instigate access to eye care, whereas for many adults, access to eye care is symptom led (Leamon *et al.*, 2014). It is widely acknowledged that the NHS sight test fee has been unsustainable for several years unless cross-subsidised by spectacle sales (Optometric Fees Negotiating Committee, 2022). Incidence of need for refractive correction is low in the overall childhood population at around 6% (Rajavi *et al.*, 2015; Hashemi *et al.*, 2018; Williams *et al.*, 2015; Cao *et al.*, 2022; Pentland & Conway, 2024) compared to close to 100% in over 50s. It is therefore not considered cost effective by many optical practices to provide sight tests to young children when no prescription is issued. Attitudes may change given the rise in childhood myopia and the financial benefits of myopia management.

A 2023 focus group study (Wilson *et al.*, 2023) evidenced time, money, attitude, awareness and communication as significant factors influencing optometrists. This study also provided useful qualitative insight into the commercial pressures placed upon optometrists which make examining children challenging. Example quotes from this work are *'we are monitored... if I don't have a conversion rate of 90% then there are questions being asked and I am not going to get that if I see children'* and *'not every parent is aware that they can come to the opticians...lot of misinformation, incorrect information and lack of communication.'*

A 2024 scoping review of the English language literature on parental knowledge and practices of child eye health care identified eleven relevant studies, only two of which were in the UK (Ghani *et al.*, 2024). Our study was one of these and the other was a qualitative survey of 20 parents of children who had failed vision screening (Bruce *et al.*, 2018b) which evidenced doubt in parents as to the benefit of treatment as well as concerns about stigma associated with glasses wear and challenges with attending multiple hospital follow up appointments. A focus group study published in 2025 (Saunders *et al.*, 2025) evidenced that parents mistakenly believe that children can reliably self-report vision problems necessitating eye examinations.

A 2025 review of the status of school vision screening globally (Little *et al.*, 2025) concluded that schools are essential in delivering health services, including vision care and this aligns with several United Nations Sustainable Development Goals (United Nations, 2025). It discusses various international models whilst acknowledging a need for better refractive service coverage. Screening is designed to prioritise sensitivity, which inevitably generates false positives. The pass/fail criteria of 0.2 LogMAR each eye has been shown to give 51.9% false positive and 7.8% false negative rates (McCullough and Saunders, 2019).

A further consideration in the context of school entry vision screening in England is that even where vision screening is provided and children who fail are followed up through a commissioned pathway, current UK protocols which measure only distance logMAR acuity can reliably detect myopia, but not hyperopia or astigmatism in school-age children. Significantly, despite this, the nationally recommended template letter for issue to parents/carers following passed screening does not state that screening may fail to pick up some visual defects (Gov.UK, 2017). Thus, avoidable vision impairment may not be identified with current screening protocols (O'Donoghue *et al.*, 2012). Public health messaging on vision screening does not highlight the high rate of false positives or potential for false negatives.

Submitted publication contributing to this theme:

Donaldson, L. A., Subramanian, A., & Conway, M. L. (2018). Eye care in young children: A parent survey exploring access and barriers. *Clinical and Experimental Optometry*, 101(4), 521–526. <https://doi.org/10.1111/cxo.12683>

Our study explored parental knowledge, attitudes, and barriers to eye care access for children aged 4 to 6 years in London, England, drawing from a sample of 384 completed questionnaires (see Appendix 4 for copy of the questionnaire). The questionnaire was purpose-designed to explore parental experiences of accessing eye care for young children, as no validated instrument existed for this specific context. Questionnaire design was informed by relevant literature and the research team's clinical experience in paediatric eye care. Draft versions of the questionnaire were piloted with a small group of parents, representative of the intended respondent population, to assess clarity, acceptability, response burden and feasibility of completion. Feedback from piloting informed minor refinements to wording and question order to improve readability and reduce

ambiguity. Formal psychometric validation was not undertaken, as the study was exploratory and no appropriate comparator instrument existed.

Key findings

The paper adds to the existing literature by evidencing both practical and perceptual barriers to timely paediatric eye care.

- *Low Awareness of Screening among parents:* Only 15% of parents whose children attended a school with a vision screening programme were aware of the programme. This mirrors findings in a similar study in the USA (Su *et al.*, 2013), where poor follow-up was attributed to lack of awareness of screening outcomes.
- *Ethnicity and Access:* Ethnicity emerged as a significant factor. Parents of African and Asian backgrounds reported more barriers and were more likely to have misconceptions —aligning with studies in other areas of healthcare showing underutilisation of healthcare among ethnic minorities (Nazroo *et al.*, 2009; Williams *et al.*, 2019). A recent study in the USA showed higher incidence of presenting visual impairment in young people from black backgrounds (Adomfeh, Jastrzembski & Oke, 2022).
- *Knowledge Gaps and Misinformation:* We evidenced a number of parental misconceptions. One-third of parents believed occasional eye turns are normal in 1–7-year-olds. Forty-eight percent of parents believed glasses strengthen vision, but the majority were either unsure or believed glasses could make the eyes weaker. A third of these parents in London, UK didn't know how or where to access an eye test.
- *Mistrust and Perception of Optometry:* Some parents expressed concern that optometrists might prescribe glasses unnecessarily, reflecting the “retail optics” concern noted by previous studies e.g. (Shickle, et al., 2015a; Shickle et al., 2015b).
- *Perceived Child Readiness:* 6–9% of parents believed their child was too young or couldn't be tested due to not knowing letters—suggesting lack of awareness about child-friendly testing methods.
- *Low Parental Concern over Educational Impact:* Despite evidence linking visual problems with academic performance (Bruce et al., 2018a; Vaughn et al., 2006), few parents would seek eye tests in the presence of signs of learning difficulty or poor concentration.

Contributions to the Field

The study reinforces and expands on earlier work by:

- Quantifying perceived barriers across multiple demographic cohorts (the sample is limited to London).
- Demonstrating how a lack of clear, standardised referral pathways post-screening hinders effective follow-up (as noted by Solebo *et al.*, 2012).
- Highlighting ethnic disparities in knowledge and access, underscoring the need for culturally sensitive, multilingual communication strategies.

Enablers to accessing eye care proposed based upon our study and other work:

- *Proactive Referral*: Direct referral to diagnostic services post-screening (rather than parent-led follow-up) is recommended to reduce inequities. A subsequent study which explored eye care practitioners' views (Cassetti *et al.*, 2019) made this recommendation and it is now included in the UK government vision screening guidelines (National Screening Committee, 2023).
- *More accessible post-screening pathways*: These referrals need to be into accessible pathways such as school or community based post-screening pathways. An example is the 'glasses in classes' project, which provides refractive care in the school setting (currently ongoing)(Centre for applied education research, 2019) or community based post-screening pathways such as the Local Optical Committee Support Unit (LOCSU) diagnostic pathway following child vision screening discussed further in Theme 2.
- *Parental Education*: Our paper contributed to the evidence for better parent education on visual development, testing, and the limitations of screening.
- *Service Visibility*: Addressing the gap in service awareness could involve routine signposting to paediatric higher qualified optometrists and making specialist credentials publicly searchable (e.g. on the General Optical Council register).
- *Standardised Communication Tools*: Use of leaflets, multilingual materials and digital resources, particularly after school screening, could enhance understanding and compliance.

Our study adds to evidence supporting the need for systemic changes in paediatric eye care delivery in the UK. It complements the broader body of literature by stressing the

intersectionality of ethnic background, knowledge, and service structure in shaping access to care. Barriers are informational and perceptual as well as practical.

Evidence of impact

Government guidelines for England now recommend establishment of local onward referral pathways for children who fail vision screening (Public Health England, 2019). Our research highlighting the lack of parental awareness, along with other papers cited above, contributed to this being published. Having a pathway in place should improve access to timely diagnosis and treatment. The Local Optical Committee Support Unit (LOCSU, 2020) is a national body established to support Local Optical Committees which in turn support their local NHS GOS contractors and performers. A key role of LOCSU is to develop standard pathways for enhanced eye care services that can be commissioned locally by NHS Integrated Care Boards in addition to the standard GOS sight test. LOCSU convened an expert working group, of which I was a member, to develop a model service specification for a community-based children's eye care service for all children failing, or unable to complete, school entry vision screening. Our study (Donaldson, Subramanian and Conway, 2018) has been used as evidence for the need for a paediatric eye care pathway to ensure children failing school vision screening are referred into an eye care service. It was used to influence the successful commissioning of the Children's screening pathway (Primary Ophthalmic Solutions, 2025) across South East London. Similar pathways are now established across twenty other NHS local areas in England. As highlighted above, good parent education and information should be implemented in conjunction to a proactive referral pathway following failed screening.

Areas for further research

Much data has been produced from these post screening community children's pathways which further studies could evaluate. This could provide evidence of the efficacy of primary vision screening as well as of the pathway itself. Parental satisfaction with the model could also be explored. This evidence could be used to influence wider commissioning of the service and/ or improvements to it.

This community-based pathway, is likely to be more convenient for parents and children, serving as a 'one stop shop' for an eye test and the provision of spectacles. It also helps to reduce the burden on paediatric ophthalmology clinics, which is the second theme of this thesis.

Theme 2: Reducing the burden on secondary paediatric ophthalmology care

Background: The case for reducing the burden on secondary paediatric ophthalmology care

Demand for secondary care ophthalmology services has been rising steadily since 2012 with the total ophthalmology waiting list then 256,000 rising to 431,000 in 2020, an increase of 175,000 or 68% (PA Consulting, 2024). A 2023 Royal College of Ophthalmologists briefing (Royal College of Ophthalmologists, 2023) highlights UK-wide ophthalmology capacity challenges with paediatric ophthalmology being especially stretched. In a recent national survey of ophthalmologists, 59.6% of consultants reported one or more departmental paediatric ophthalmology vacancy and 87% of trainees reported they would not choose paediatric ophthalmology, citing the complex nature of paediatric cases and discomfort examining children (Clough, Magan and Jain, 2025). This indicates the problem is set to worsen in the short term, hence solutions to use community-based services need to be considered.

Ophthalmology also carries one of the largest outpatient backlogs. In recent national data, over 630,000 patients were waiting for an ophthalmology appointment in England, representing around 8–10% of the total NHS waiting list, despite ophthalmology accounting for a much smaller proportion of the overall workforce (Royal College of Ophthalmologists, 2022). Importantly, these figures substantially under-represent true demand, as NHS waiting-list statistics largely exclude follow-up appointments. Follow-ups account for approximately 69% of all ophthalmology outpatient activity, creating a large “hidden backlog” that is not routinely visible in national reporting (Royal College of Ophthalmologists, 2022). Patient-reported data further show that prolonged waits are associated with deterioration in vision and quality of life, with around 70% of patients reporting worsening vision while waiting for specialist eye care (Rees, 2023).

Against this backdrop, avoidable referrals represent a critical pressure point. Ophthalmology services receive a high volume of referrals that do not ultimately require hospital-based care (Verma *et al.*, 2025). Reviews of referral accuracy consistently identify false-positive referrals—patients referred to hospital who are discharged at first visit or require no specialist treatment—as a significant contributor to oversubscription of hospital eye services (Carmichael *et al.*, 2023).

This phenomenon is particularly relevant in the context of population screening and early detection programmes. As already stated in Theme 1, screening is designed to prioritise sensitivity, which inevitably generates false positives, but when these referrals are not effectively filtered or managed within community pathways, they add to secondary care demand without corresponding clinical benefit. National policy responses, including referral filtering schemes, enhanced community optometry pathways and single points of access, explicitly aim to reduce unnecessary hospital attendances while maintaining patient safety, recognising that capacity in secondary care must be reserved for those at genuine risk of sight loss.

In this context, understanding and minimising avoidable onward referral following school-entry vision screening is not simply a matter of test accuracy, but of system sustainability. Reducing unnecessary demand on secondary care ophthalmology is essential to protect timely access for patients with progressive or sight-threatening disease, and to prevent avoidable harm arising from delayed diagnosis or treatment. This places increasing importance on robust screening protocols, clear post-screening pathways, and accurate public health messaging, so that the benefits of early detection are not undermined by unintended pressures on specialist services.

Publications submitted contributing to this theme:

Karas, M. P., Donaldson, L. A., Charles, A., Silver, J., Hodes, D., & Adams, G. G. W. (1999). Paediatric community vision screening—a new model. *Ophthalmic and Physiological Optics*. <https://doi.org/10.1046/j.1475-1313.1999.00425.x>

Donaldson, L. A., Karas, M. P., Charles, A. E., & Adams, G. G. W. (2002). Paediatric community vision screening with combined optometric and orthoptic care: A 64-month review. *Ophthalmic and Physiological Optics*, 22, 26–31. <https://doi.org/10.1046/j.1475-1313.2002.00001.x>

In the late 1990s, whilst working as an optometrist in Moorfields Eye Hospital's consultant led hospital based paediatric clinics, waiting lists for these clinics were long and there were high numbers of missed appointments. Basic analysis of the clinic activity and referrals suggested that most children attending needed only spectacles or, less often, patching therapy. We hypothesised

that these children could potentially be managed without routine consultant ophthalmologist input, in a more convenient and familiar setting, which may also have the added benefit of improving rates of attendance. We established a clinic in an area of high socio-economic deprivation in a local community health centre, to assess children failing school entry vision screening, as an outreach of the Hospital Eye Service. We carried out a service evaluation, initially publishing a paper describing the model (Karas *et al.*, 1999) and then publishing a review of the data from an evaluation of the service over a 64-month period (Donaldson *et al.*, 2002) during which 755 new patient appointments and 4609 follow up appointments were audited.

Key Findings

We evidenced good attendance levels and an ability to manage most cases (84%) without need for an ophthalmological opinion. The model incorporated spectacle dispensing to offer a convenient all-in-one service, making sure that patients received properly fitted spectacles - the main prescribed treatment. Most referrals into the clinics were from school nurses, the remaining third of referrals were from community medical officers and GPs. Our findings showed that 41% of children seen were prescribed glasses and 8% patching. Ninety-eight per cent of the children who attended saw the orthoptist. The majority of the children who attended were within normal limits orthoptically (83%, 1079 patients). For 7% a convergent squint was recorded, for 5% a divergent squint and in 4% of cases some other orthoptic anomaly was noted. Sixteen per cent of the children who attended required onward referral to the HES, the majority of these (61%, 141) for strabismus. The most common refractive error was hyperopic astigmatism (24%), followed by simple hyperopia (16%) and then mixed astigmatism. Simple myopes made up 6% and myopic astigmats 5% of cases. 19% has anisometropia ($>0.75D$ difference in any meridian). Following combined orthoptic and optometric testing 43% could be discharged without treatment or referral.

Contribution to the field

The model evaluated in this research was for joint orthoptic and optometric care in a hospital outreach clinic and proved to be effective in eliminating the need for ophthalmological input in 84% of cases failing school vision screening.

Subsequent studies have evidenced the clinical safety and cost benefit of community-based eye care pathways for minor eye conditions and glaucoma referral refinement in the wider population conditions (Kanabar *et al.*, 2022;Konstantakopoulou *et al.*, 2014, 2018; Mason *et al.*, 2017).

Access to low vision services in Wales has improved following establishment of a national primary care based low vision service; these services had previously been accessed in the hospital setting. A hospital-based service created significant geographic inequity, conversely provision from community optometry practices brought services closer to patients' homes, with reduced journey times for 80% of patients. The model also reduced waiting times and increased capacity significantly by utilising upskilling of the primary eye care workforce (Ryan *et al.*, 2010). No similar study has been carried out to evaluate the transfer of paediatric eye care service to community in the UK. Publication of such evaluation would strengthen the evidence base for the model.

A more recent review of school vision screening similarly identifies poor spectacle wear as a key implementation challenge that attenuates educational and visual benefits, even where screening sensitivity and referral pathways are robust (Little *et al.*, 2025).

Across childhood populations, meta-analysis of international randomised trials found that free spectacle provision more than doubles compliance with spectacle wear compared with control conditions (Wu, Feng and Zhang, 2023). Even with free provision, adherence remains incomplete and often declines over time, highlighting persistent behavioural and contextual barriers to sustained wear. Notably, there is limited UK-specific evidence examining how service design, follow-up arrangements, and public health messaging influence longer-term adherence. This gap has implications for interpreting screening effectiveness and for understanding how poor adherence may contribute to apparent treatment failure and ongoing demand on secondary care.

The detrimental impact of non-adherence with spectacle wear is supported by longitudinal outcome data. A UK-based cohort study following children after school-entry vision screening demonstrated that children who consistently wore prescribed spectacles showed greater improvements in visual acuity and early literacy, whereas non-adherent children derived little functional benefit from correction (Bruce *et al.*, 2018a).

Evidence of Impact

Evidencing that 84% of the children failing school vision screening could be managed without ophthalmological input (Donaldson *et al.*, 2002) led to the widespread replication of optometrist/orthoptic led community paediatric eye clinics as outreaches of the Hospital Eye Service, by Moorfields Eye Hospital and more widely by other trusts.

Another model of community paediatric eye care is the LOCSU diagnostic pathway following child vision screening (LOCSU, 2020). This uses community optical practices (opticians) to provide a service locally commissioned by the NHS Integrated Care Board (ICB) in addition to the GOS sight test. It uses existing NHS eye care infrastructure, where the majority of optometrists practice in the UK, to provide a post-failed screening pathway. All children have a full visual assessment, cycloplegic refraction and follow up as part of the commissioned service and the NHS GOS voucher system is used to provide glasses. Advantages are a maximum waiting time of two weeks from failed screening, reduced waiting times for secondary care for the minority of children who do require ophthalmological or orthoptic input and a reduction in costs when compared to a model where all children who fail screening are referred to the hospital eye service.

This service is established across South East London ICB – there are approximately 18,475 children in reception year across the area.

Areas for further research

There is currently a lack of published evidence base for this LOCSU model, and as our peer reviewed model included the expertise of an orthoptist, it is not directly comparable. We propose further service evaluation of these pathways and research to validate and refine a best practice model.

Understanding a need for targeted pathways for children led to an exploration of this for another vulnerable group, people with learning disabilities, including children and young people attending special schools. Submitted publications focussed on these targeted pathway (Royal College of Ophthalmologists, 2016; Donaldson, O'Brien & Karas, 2018; Donaldson *et al.*, 2019; Donaldson & Karas, 2020; Pilling *et al.*, 2022) will also help to reduce the burden on secondary care clinics and are discussed further in Theme 3.

Theme 3 Developing and testing specialist targeted eye care pathways for the learning-disabled population

Background

The case for targeted eye care pathways for the learning-disabled population

There is much anecdotal evidence, and some evidence in the grey literature that people with learning disabilities often experience barriers to accessing eye care in community opticians/optometrists under the NHS General Ophthalmic Service contract (The General Ophthalmic Services Contracts Regulations 2008). These barriers include difficulties with appointment booking systems, time-limited testing environments, reliance on verbal communication, unfamiliar clinical settings, and limited practitioner confidence in adapting assessments for individuals with complex needs (Healthwatch, 2020). As a result, people with learning disabilities may struggle to access community eye care at all, receive incomplete or sub-optimal assessments, or be referred directly to secondary care without meaningful assessment in primary care. Consistent with this, anecdotal experience and personal communication with hospital orthoptists and optometrists indicates that many people with learning disabilities are being seen for routine regular eye care in the hospital setting. While this practice may ensure that some level of eye care is provided, it is inefficient, places additional burden on secondary care services, and may inadvertently reinforce inequitable access by normalising hospital-based care as the default pathway for this population.

As previously highlighted in the background section (page 11), the majority of the published evidence of eye care need in the learning disabled adult population has been in patients who self-present and so tend to have less profound disabilities (Woodhouse, Griffiths and Gedling, 2000; Woodhouse, Adler and Duignan, 2003, 2004). This introduces an inherent selection bias and likely underestimates both the prevalence and complexity of unmet eye care need among adults with more profound learning disabilities. Whilst further research evidencing unmet eye care need in the adult learning-disabled population would be advantageous, we can hypothesise that the high level of unmet need in the special school population is likely to indicate an equivalent or worse level of unmet need in the adult population. This is because individuals are less likely to have continuity in

supporters/ carers and so health and eye care information may get lost or be poorly understood. In addition, as with the overall population, incidence of eye problems will increase with age. For adults with learning disabilities, this occurs alongside a high burden of multimorbidity competing with the need to access eye care – adults with learning disabilities have on average eleven co-existing health conditions (Kinnear *et al.*, 2018). These competing health demands can further deprioritise routine eye care, even when visual difficulties have a significant impact on function, communication and quality of life.

In this context, reliance on standard, non-adapted eye care pathways is unlikely to deliver equitable outcomes. Generic pathways assume a level of health literacy, communication ability, behavioural compliance and system navigation that make them inaccessible to people with learning disabilities. Targeted eye care pathways—designed explicitly around the needs of this population—offer a mechanism to address these structural inequities. Such pathways may include extended appointment times, adapted assessment techniques, enhanced carer involvement, improved information transfer, clearer referral criteria, and closer integration between community and secondary care services (LOCSU, 2020a; Public Health England, 2020).

Developing and testing specialist targeted eye care pathways therefore aligns with broader NHS commitments to reasonable adjustments, health equity and prudent healthcare (HM Government, 2010). By enabling appropriate assessment and management in primary or community settings wherever possible, targeted pathways have the potential to improve access, reduce inappropriate secondary care use, and ensure that hospital eye services are reserved for individuals with complex or sight-threatening conditions. This theme seeks to address a critical gap in the evidence base by examining how such pathways can be designed, implemented and evaluated for adults with learning disabilities, and by exploring their impact on access, quality and sustainability of eye care provision.

Autism Spectrum Disorder

33% of people with Autism Spectrum Disorder (ASD) also have a learning disability (Zeidan et al., 2022). Autistic people have been shown to have a distinct visual and sensory profile with a higher prevalence of visual difficulties including refractive need, cerebral visual impairment and ocular pathology, but also atypical visual processing, communication differences, sensory sensitivities

including heightened sensitivity to visual detail, differences in contrast sensitivity, atypical motion perception, and difficulties with visual integration and visual crowding (Kielinen et al., 2004; Behrmann et al., 2006; Anketell et al., 2013, 2015; Croen et al., 2015; Posar and Visconti, 2017; Little, 2018; Rydzewska et al., 2019). Sensory processing differences mean standard optometric and ophthalmic environments, which are often busy, brightly lit, and time-limited, can be overwhelming and may inhibit successful assessment. Spectacle wear may also be challenging due to tactile sensitivity, altered proprioceptive awareness, or discomfort associated with changes in visual input. Without structured, individualised support, this may result in reduced tolerance of spectacles and lower adherence, even when refractive correction is clinically appropriate. Generic eye care models prioritise efficiency and standardisation, rather than flexibility, disadvantaging autistic individuals who require additional time, alternative communication strategies, visual supports, or environmental adaptations to engage optimally with assessment.

First publication submitted contributing to this theme:

Donaldson, L. A., Karas, M., O'Brien, D., & Woodhouse, J. M. (2019). Findings from an opt-in eye examination service in English special schools: Is vision screening effective for this population? PLOS ONE, 14(3), e0212733. <https://doi.org/10.1371/journal.pone.0212733>

Contributions and key finding

We wished to explore if people with significant learning disabilities are accessing the eye care they needed. Recruiting to assess large numbers of people with moderate to severe learning disabilities would be challenging and so supported by SeeAbility, I was clinical lead for a 'research in action' project established in special schools. Research in action describes a model in healthcare where practitioner researchers investigate and evaluate their own work with a view to generating new knowledge and simultaneously improving practice (Vallenga *et al.*, 2009). A Research-in-Action (RiA) approach was selected because the aims of our programme of work were not only to generate evidence, but to improve access to eye care whilst exploring models of care.

Research-in-Action enabled the research to be conducted alongside service delivery, allowing iterative refinement of methods. This flexibility was essential when working with a heterogeneous

population with complex needs, where rigid protocols could have excluded those most at risk of unmet visual need.

For the research team, the approach supported close collaboration with schools, families and multidisciplinary professionals, improving engagement and data quality. Importantly, it ensured that participation offered direct benefit through access to eye examinations and onward care, rather than extracting data without service gain. The findings from the 2019 study therefore had immediate relevance for service design, demonstrating that conventional vision screening was insufficient for this population and informing subsequent development of targeted eye care pathways and policy.

With Department of Health Innovation funding, based on the findings of previously published studies of this population (Das *et al.*, 2010; Woodhouse *et al.*, 2014; Pilling & Outhwaite, 2017), we explored and met the eye care needs of the students attending nine special schools in London, Manchester and Durham.

All these previous studies of the eye care needs of special school students consistently evidenced substantially higher rates of visual impairment than in the general population, much of which is preventable or treatable yet remains unrecognised and unmet (Das *et al.*, 2010; Woodhouse *et al.*, 2014). Das *et al.*, 2010 evaluated the provision of an ophthalmologist-led school service in Scotland for 240 children, 46.1% needed glasses and only 48% of the children requiring glasses were wearing the glasses they needed. The paper showed that conditions such as refractive error and strabismus are both highly prevalent and frequently undiagnosed, with visual difficulties often attributed to the learning disability itself rather than investigated as distinct clinical issues, illustrating the impact of diagnostic overshadowing. Woodhouse *et al.*, 2014 presented an optometrist led model which assessed 228 children in Wales; 46% needed glasses with 38% had no previous eye care history reported – the paper further demonstrated that conventional visual acuity testing frequently underestimates functional vision in this population, as difficulties with communication, cognition or test design can mask usable vision, highlighting the necessity of adapted assessment techniques and specialist expertise. Pilling and Outhwaite (2017) reported on their findings as an ophthalmologist/ orthoptist team for 147 children attending special schools in Bradford, Yorkshire not under hospital eye care. Of these children, 33% had a visual impairment, 17% were prescribed glasses for the first time and 31% had significant refractive error (14% had previously been prescribed glasses). At 6 month follow up, without a spectacle dispensing service in school, only

20% of the children who would benefit from glasses were using any. For special school students, prescriptions are often higher, issues with glasses fit and comfort may be more challenging to communicate and address, there may be compounding sensory challenges, parents have competing health needs to manage and there may be misconceptions around accuracy of prescribing for children where subjective responses are difficult or impossible. For some students there is also an increased incidence of breakages due to behavioural or physical challenges.

The findings from Pilling and Outhwaite (2017) prompted the inclusion of spectacle dispensing, and ongoing support with spectacles and adaption to wearing them, in the model of care our team provided.

Our paper (Donaldson *et al.*, 2019) evidenced that screening was not appropriate for this group as half of all the children had a significant visual problem and only one of the school entry age children (n=156, 0.6%) passed the national screening committee recommended vision screening. In this, the largest published study of this population's eye care needs to date (n=949), we published broadly similar findings to the previously published UK studies (Das *et al.*, 2010; Woodhouse *et al.*, 2014; Pilling and Outhwaite, 2017). 12.5% of all children examined (119/949) were found to have a visual deficiency that had not been previously identified, indicating a significant level of unmet need prior to the school-based eye-care intervention. Eye-care history was available for 847 children, of whom 44.0% had no recorded history of any previous eye care, highlighting poor access to routine eye-care pathways before service delivery. 46.9% had previously attended a hospital eye service at some point. Only 10.7% of children with an available history had previously attended a community optical practice, demonstrating low uptake of standard primary eye-care services in this population. Spectacle correction was required for 31.5% of children assessed (299/949), with 12.9% receiving spectacles for the first time, quantifying both the scale of refractive need and delayed access to correction. 3.1% of children (29/949) were referred for a medical opinion. For 1.8% (17/949) the referral was for an ophthalmologist's opinion, despite the high prevalence of visual impairment identified, demonstrating that the majority of need was appropriately managed within an adapted primary eye-care model (in cases of stable, unavoidable visual impairment, having been confirmed medically historically).

51.9% of the children had a diagnosis of autism in addition to learning disability and these children were statistically significantly less likely to provide a reliable visual acuity measurement.

Contribution to the field

Our findings (Donaldson *et al.*, 2019) reinforced those of earlier, smaller studies, highlighting a substantial unmet need for eye care need and evidenced that vision screening is not appropriate for the special school population.

Second publication submitted contributing to this theme:

Framework for provision of eye care in special schools in England (2016). SeeAbility (lead Lisa Donaldson), Framework group. <https://www.rcophth.ac.uk/resources-listing/framework-for-provision-of-eye-care-in-special-schools-in-england/>

In parallel to the clinical activity delivered to gather the data for (Donaldson *et al.*, 2019), in my role at SeeAbility, I chaired a Task and Finish group of representatives of all the eye care professional bodies to produce a framework model of eye care for children attending special schools in England (Royal College of Ophthalmologists, 2016). The special schools eye care framework was developed using a mixed-methods, co-production approach that combined epidemiological evidence, service evaluation data and stakeholder expertise. The methodology integrated findings from population-level research on unmet eye care need in special school populations with iterative consultation involving clinicians, educators, families and people with lived experience of learning disability. Service design was informed by pilot delivery in special school settings to refine assessment protocols, referral pathways and information sharing. The framework prioritised equity-focused design principles, including reasonable adjustments, integration with existing education and health systems, and aligns with national policy commitments to preventive, community-based care.

The paper provides a consensus recommendation for a school- based model of care for this patient group, for whom rates of failure to attend hospital eye clinic appointments are high at 54% (Imor *et al.*, 2014).

Donaldson *et al.* (2019) evidenced 45% of children attending special school had no reported eye care history, with this figure rising to 75% for students with autism. There is evidence (Bottini *et al.*, 2025) that 38% of behaviour clinic appointments are cancelled for autistic children with challenges around sleep, attendance, time-keeping and new environments cited as reasons for cancelling.

Many children who attend special schools have multiple and complex health needs and sensory needs may not be considered, prioritised and/or understood.

Key recommendations

The task and finish group developed the Framework for provision of eye care in special schools (Royal College of Ophthalmologists, 2016). The group acknowledged that the risk of diagnostic overshadowing in this patient group is high – signs of poor vision may be attributed in error to a child's learning disability, as there is considerable overlap. Whilst it can be hypothesised that their neurotypical peers may report deteriorating vision with the onset of myopia, challenges around communication mean this is less likely to occur for children attending special schools. Therefore, the Framework paper (Royal College of Ophthalmologists, 2016) recommends that this group receive routine eye care at least annually throughout school years, up to age 25 years. An in-school model provides preventative, timely care, removing wasted appointments resulting from children not attending hospital eye clinics as in the school setting substitutions can be made if children are absent or not able to participate on the clinic day. The setting is familiar and multiple assessment attempts can be made if necessary. The Framework paper (Royal College of Ophthalmologists, 2016) recommends that there should be continuity of clinical care whenever possible to reduce stress for the children which will also have the positive outcome of improving clinical assessments.

Additionally, it recommends that spectacle dispensing and support with wearing spectacles be included as part of the service, drawing on insights from Pilling and Outhwaite (2017). Using a pre-appointment questionnaire (see Appendix 5) to gather as much information as possible on visual signs, symptoms and eye care history in advance ensures that all valuable time with the child during the appointment is focused on clinical assessment.

The model also enables the eye care team to become part of the school's multidisciplinary team that supports the child. It recommends a written report is completed for every child and shared with parents/ carers and with the team around the child, teaching staff but also, where relevant, other professionals including Qualified Teachers for the Visually Impaired (QTVIs), speech and language therapists (SaLTs), Occupational Therapists (OTs), physiotherapists and paediatricians. A report template was developed through a collaboration between SeeAbility and Ulster University (see Appendix 8) and completion of this is required for all NHS special schools eye care service

appointments. (NHS England, 2025). The team in Ulster carried out an in-school eye care service in Northern Ireland, the SEE project, which utilised the same report (Black *et al.*, 2019) and evidenced that the service measurably improved students' vision and behaviour. They also evidenced provision of written reports is highly valued by parents and teachers (E McConnell *et al.*, 2019) to help them in understanding how a child sees and what adaptations are needed to support them to achieve optimal visual function. The information provided by a Vision Report was deemed useful day-to-day by 78.3% of parents and 100% of teachers. The majority (80%) of teachers implemented classroom modifications suggested in the report, 47.9% of parents reported implementation of modifications at home (McConnell *et al.*, 2019).

Having an eye care service present in the school and providing a plain English written report ensures that teaching staff are better informed about their student's visual abilities and needs. They can support them to successfully adapt to spectacles and apply appropriate strategies to support uncorrectable visual needs – such as positioning in the classroom for children with nystagmus or a visual field defect or applying strategies to support individually assessed needs associated with cerebral visual impairment. The framework paper provided an overview of which clinical assessments should be undertaken and equipment needed to provide the service. This has been used by NHS England to inform the development of a national specification for a service which was published in March 2025 (NHS England, 2025).

The Framework for provision of eye care in special schools (Royal College of Ophthalmologists, 2016) recommends close working with local hospital eye clinics. Referral rates into secondary care from SeeAbility's service were low at 1.8% (Donaldson *et al.*, 2019) with referrals to ophthalmology for suspected keratoconus, previously undiagnosed or uncertified cerebral visual impairment and previously undiagnosed cataract. Of all the children seen, 1.3% were referred to their GP for management of conjunctivitis/ blepharitis (an independent prescriber optometrist providing the service would now avoid the need for these referrals). The service included an orthoptic referral clinic and 3.4% were referred for an orthoptic opinion. The majority of identified unmet need did not require referral to secondary care, being refractive error or cerebral visual impairment (cerebral visual impairment is typically present from birth and not progressive). Establishment of good links with local hospitals allows discharge of stable children into the service who would otherwise remain under hospital paediatric ophthalmology services. Eighty-nine percent of children seen had eye care history reported by their parent/carer. Of these, 22% were under hospital care, with a further 22%

having a history of hospital eye care history but no community follow up reported after discharge. Close relationships with local authority QTVIs allow appropriate adaptations to teaching resources to accommodate children's visual needs. The model also allows information sharing with speech and language therapists, to inform decisions around communication strategies – the eye team can advise if children can access eye gaze communication technology for example, or accessible font sizes for communication devices. The Framework paper (Royal College of Ophthalmologists, 2016) recommends an opt-out model of care, so that parents are sent information on the service and requested to provide eye care history, but their child will be seen unless they actively request for them not to receive the service.

The paper also recommends '*The development of a nationally recognised accreditation for working with children with learning disabilities is proposed and this should become mandatory for all professionals working in a Special Schools Ophthalmic Team*'.

In 2021/22 I led SeeAbility's eye care team in delivering a pilot special school's eye care clinician's training programme, funded by and co-delivered with NHS England. This was completed by 61 clinicians (32 optometrists and 29 dispensing opticians) in the North East of England, 27 (15 optometrists and 12 dispensing opticians) in the North West of England and 17 (8 optometrists 9 dispensing opticians) in London. Completion was a requirement of NHS England for accreditation to provide the nationally commissioned proof of concept NHS England special schools eye care service. In 2023/2024, I led the development of a 15 credit, level 7 postgraduate training module which SeeAbility and City, St George's, University of London are delivering to accredit clinicians to provide the service. 23 clinicians have enrolled on the module in its first year of running (2025/2026).

Evidence of impact

Prior to this work, no qualification for eye care professionals existed to equip them specifically to meet the eye care needs of learning-disabled children. A specialist and accredited workforce remain a recommendation of NHS England and supports clinical excellence and optimal outcomes for the students (HealthEducationEngland, 2017). Best practice also recommends establishment of local special school eye care clinical provider special interest groups and regular peer discussion continued professional development (CPD) sessions to foster a community of specialists and sharing of best practice. This has been formally established for SeeAbility's clinical team.

Third publication submitted contributing to this theme:

Donaldson, L.A., Patel, M, O' Brien, D and Karas M. (2025). Parental satisfaction with a special schools eyecare and spectacle dispensing service. *British Journal of Visual Impairment*.

<http://dx.doi.org/10.1177/02646196251382450>

Contribution and key findings:

Since the SeeAbility special schools eye care service was established in 2013, SeeAbility have carried out an annual satisfaction survey of all parents and carers of children receiving the SeeAbility service. This paper presents the findings, and a thematic analysis, of this survey in 2023; the survey is reproduced in Appendix 6.

Since 2014, the questionnaire has been refined in response to feedback from parents, clinicians and educators, allowing items to be clarified, removed or added as service models and research questions evolved.

The 2023 iteration of the questionnaire was informed by this longitudinal refinement process, findings from earlier phases of the research programme, and relevant literature on access to eye care for children with complex needs. Content validity was supported through review by the multidisciplinary research team, including optometrists, orthoptists, learning disability specialists and researchers experienced in working with families of children attending special schools. This review focused on relevance, clarity, sensitivity of language and alignment with the study aims.

Given the service-evaluation focus of the survey, and the absence of an appropriate validated comparator instrument, formal psychometric validation was not undertaken.

The paper supports the findings of an NHS independent evaluation of the wider proof of concept special school eye care service (NHS England, 2023), evidencing high levels of patient satisfaction with the service provided. Four hundred and seventeen parents responded to the survey (19.2% response rate from 2186 surveys distributed). Ninety six percent of respondents were satisfied with the SeeAbility special school eye care service. Eighty four percent of parents identified school as their preferred setting for their child's eye care and 80% also preferred it as the place for their child's spectacles to be dispensed. Ninety two percent of parents reported a better understanding of their child's visual abilities, needs and limitations. This provides further evidence of the value of a plain English written report as evidenced by (E McConnell *et al*, 2019; NHS England, 2023).

Our thematic analysis of open-text responses to service feedback requests (using NVivo 14) revealed positive emotional responses and favourable outcomes associated with the service, specifically the successful completion of eye examinations and visual correction with spectacles, leading to improved visual outcomes. A common theme was difficulty in keeping hospital appointments due to the stress and anxiety they cause (explaining the high level of non-attendance evidenced (Jmor *et al.*, 2014)). Parents also reported being refused access to primary eye care on the high street. This supports previous studies evidencing a lack of accessibility to primary eye care services (Wilson *et al.*, 2021; Shah *et al.*, 2007). Parent comments also further evidence the finding of (Donaldson, Subramanian & Conway, 2018) that there is a public perception that eye tests are only possible if a person can subjectively engage with assessment, which will likely lead to not attempting to access primary eye care.

Evidence of Impact

Presentation of the Framework for provision of eye care in special schools paper (Royal College of Ophthalmologists, 2016), along with the evidence of high levels of unmet need in English special schools (Pilling & Outhwaite, 2017; Donaldson *et al.*, 2019) to NHS England has led to a governmental commitment to a national rollout of eye care in all special schools in England.

NHS England commissioned this service as a proof-of-concept model in 83 English special schools in April 2021, reaching an estimated 10% of the English special school population. The service was very positively independently evaluated in 2023 (NHS England, 2023), 75% of 115 school staff responding to a survey from schools in receipt of the service stated that it had had a significant positive impact on students' learning and behaviour, including '*cases of children who it was believed had serious behavioural issues who were, in fact, suffering from not being able to see, and that this was the cause of their lack of engagement at school*'. The evaluation commissioned by NHS England found that 97% of school staff rated the service good or excellent and 90.1% would not change anything about the service. Sixty-six special schools with no proof-of-concept service were also surveyed and of these, 88% were keen to host a service with 58% stating there was currently no eye care provision for their students - showing high levels of demand from special schools for future roll out of new services.

In 2023, the Department for Health and Social care committed to extending the service to all special schools (Department for health and social care, 2023).

Changes to GOS regulations to establish a special schools eye care service nationally were laid in November 2024 (legislation.gov.uk, 2024) and in March 2025 NHS England issued a national service specification (NHS England, 2025) and allocated 12 million pounds in funding to the Integrated Care Boards (ICBs) to roll out the service in all schools. The NHS England specification generally aligns with the recommendations of the Framework for eye care in special schools (Royal College of Ophthalmologists, 2016), a notable difference being a requirement for opt-in consent for assessment. The national screening committee recommends screening programmes are opt-out to improve uptake (UK National Screening Committee, 2022) and it can be hypothesised that it may be difficult to obtain opt-in consent from some of the most vulnerable students who have previously not accessed eye care. The majority of school entry vision screening services in England and Wales, and all in Scotland, operate as opt-out. To give equity, the Framework paper recommends an opt out model, with opt in requirements for cycloplegic refraction and supply of spectacles.

At September 2025, SeeAbility's existing proof of concept contract has been extended so that the service is live in a further 32 special school settings, bringing the total number of schools receiving a SeeAbility service in London to 64 with 7650 children and young people able to access the service. This represents around a third of the estimated total 23,000 London special school population. In North West and North East regions, a total population of around 6000 children continue to have access to the proof-of-concept service. In October 2025, NEL ICB issued a tender for provision of the service across all 5 London ICBs with a mobilisation date of 1st June 2026.

Fourth publication submitted contributing to this theme:

Donaldson, L., & Karas, M. (2020). Optometric care of children with significant learning disabilities. *Optometry in Practice*. <https://www.college-optometrists.org/professional-development/college-journals/optometry-in-practice/all-oip-articles/volume-21,-issue-3/2020-09-optometriccareofchildrenwithsignificantlea>

Contribution to the field:

This paper provides practical guidance for clinical practice for this patient group. It outlines and provides evidence for the common aetiologies of learning disability and ocular and non - ocular associations and prevalence. Barriers to accessing eye care are presented and clinicians are encouraged to raise awareness of sight tests being accessible to all and dispel myths around access

to eye care. The paper also outlines recommended clinical and non- clinical adaptations to practice, including communication techniques and guidance and record keeping and reporting guidance.

Evidence of Impact:

Presentation of elements of this CPD accredited work prior to its publication, along with the sharing of clinician's concerns around challenges in completing all elements of assessments for patients with complex needs, led NHS England to issue guidance on examining 'challenging patients'. (NHS England, 2019).

It is hoped this guidance will facilitate more willingness to attempt assessment of this patient group by optometrists and dispensing opticians.

Fifth publication submitted contributing to this theme:

Pilling, R. F., Donaldson, L., Karas, M., *et al.* (2022). Referral thresholds for an integrated learning disability eye care pathway: A consensus approach. *Eye*, 36, 742–748.

<https://doi.org/10.1038/s41433-021-01516-y>

Contribution and key findings:

Whilst published evidence is lacking, many of the barriers to eye care discussed above for young children and children attending special school are also likely to impact on the wider learning-disabled population's access to eye care. If parents believe an eye test cannot be completed or glasses prescribed without subjective input, ((Donaldson, Subramanian and Conway, 2018; Donaldson *et al.*, 2025), it can be hypothesised that carers will believe this for adults who cannot speak or communicate easily. Anecdotal evidence suggests that the knowledge that spectacles can be prescribed based upon objective measurement of the eyes is not widespread.

The LOCSU 'Easy Eye Care Pathway' for adults with a learning disability was first developed in 2012 in response to anecdotal evidence of barriers to accessing the NHS GOS sight test.

In 2020, as a Local Optical Committee member for South East London, I instigated a review and re-design of this pathway. A working group included people with learning disabilities and/or autism employed by SeeAbility as 'Eye Care Champions' and representatives of the eye care professional

bodies updated the pathway and associated documents, broadening the eligibility to all people with a learning disability and autism – allowing a pathway for children with learning disabilities not attending special schools. Similar to the diagnostic pathway following child vision screening (LOCSU, 2020b), The ‘Easy Eye Care Pathway’ is designed to be commissioned as an ‘add-on’ to the GOS sight test and commissioned by NHS ICBs. The pathway is provided by optometrists working in community optical practices (opticians) and is designed to meet the needs of the learning disabled and autistic population. Optometrists who provide the service complete additional training in meeting the eye care needs of this population, this five-hour training was produced by our SeeAbility clinical team and Eye Care Champions in 2020 (provided via WOPEC, the Welsh Optometric postgraduate Education Centre). The pathway utilises existing NHS eye care infrastructure, where most optometrists practice in the UK. Hospital ophthalmology departments, struggling with capacity (Royal College of Ophthalmologists, 2018; Royal College of Ophthalmologists, 2022) are keen to discharge to community optometrists. This service, when commissioned, makes that possible. As in the special school eye care ‘in school’ model, a pre-appointment ‘About me and my eyes’ questionnaire is used to gather history and sign/symptoms information in advance and encourage observation and consideration of visual abilities ahead of the eye test. After the test a ‘Results of my Eye Test’ form is completed to encourage dissemination of plain English information ensuring that each individual’s visual needs are optimally understood and met by their supporters. This pathway provides a model that, if commissioned, ensures people of all ages with learning disabilities and/or autism receive care from clinicians with additional training and adequate funding to provide fully reasonably adjusted care in community optical practices.

The original 2012 pathway specification had raised concerns with commissioners that it would lead to high levels of referral on to secondary care. Clinicians providing the pathway where it was commissioned previously had also expressed challenges with knowing what clinical presentations should initiate onward referral, and such clinical guidelines were not available in the literature or from professional bodies. In response to this we were keen to develop referral guidelines for the pathway. Our paper (Pilling *et al.*, 2022) used a consensus approach to develop guidance for optometrists seeing people with learning disabilities and autism.

The lead author carried out individual online interviews with all the contributors, detailed notes were taken and collated into an initial working document combining qualitative input from all participants on thresholds for referral for an ophthalmological opinion. Alongside eye

condition-specific feedback, contributors articulated overarching decision-making principles that guided their referral behaviour in practice; these principles were synthesised into a small number of shared criteria underpinning referral decisions. The draft consensus document was then circulated electronically to all participants for review. Participants were asked to comment on the accuracy of synthesis, identify areas of disagreement or ambiguity, and suggest refinements to thresholds or accompanying explanatory notes. Amendments were incorporated where there was clear agreement, and wording refined to resolve differences in emphasis. Where variation in practice existed, thresholds were framed deliberately to support professional judgement rather than impose prescriptive rules. The process concluded once all participants confirmed that the final document accurately reflected their collective clinical experience and represented an acceptable and pragmatic set of referral thresholds to support local pathway development. This approach was intended to achieve practical consensus-based guidelines for referral grounded in real-world clinical decision-making.

Critically, the paper states that inability to complete certain elements of the eye test is NOT a criterion for onward referral. In alignment with the NHS England avoidance of doubt guidance (NHS England, 2019), clinicians are encouraged to record at least a repeated attempt at any element of the eye test that has been impossible / difficult/ incomplete and record the reason why. As Professor Rachel Pilling FRCS articulates: *‘There are few ophthalmologists nationally who frequently encounter patients with a learning disability in their hospital practice and knowing where to start when creating referral criteria or KPIs may create a barrier to services becoming established. In order to address this gap in experience, we set about developing a set of consensus statements regarding referral thresholds for ocular conditions commonly encountered in adults with learning disability’*(Pilling et al., 2022).

Appendix 5 is taken from the paper and details the referral thresholds developed for common clinical findings in patients with learning disabilities.

Evidence of Impact

In 2023, this paper (Pilling et al., 2022) was used to support the successful commissioning of the pathway across South East London National Health Service Integrated Care Board and to date referral from the pathway into secondary care have been as expected with preliminary data indicating these guidelines have been successfully followed. It has also been used widely as

guidance for the providers of the pathway where it is commissioned in three ICB regions in the North West of England: Lancashire and South Cumbria, Greater Manchester and Cheshire and Merseyside and in Durham.

At October 2025 there are 103 Easy Eye Care accredited optical practices in the North West of England, 3 in Durham and 14 in South East London.

Areas for further research

Evaluation of the established pathways is recommended to encourage wider commissioning and ensure the model of care is optimal. Consideration also needs to be given to understanding how the use of community opticians affects success of the service in light of previous evidence that this setting can be a barrier due to retail associations and concerns with cost (Shickle et al., 2015a; Shickle, Davey & Slade, 2015b).

Theme 4 Exploring models of eye care advocacy and pathway promotion and satisfaction for people with learning disabilities and families/carers

Background

In 2012, there was a commitment from the NHS in England to involve individuals in decision making on their own healthcare: ‘nothing about me without me’, supported by a King’s fund report (Coulter and Collins, 2011) articulating how this could be achieved. Since that time evidence has shown that co-production of services tends to lead to better results than healthcare providers, researchers, or policy makers acting on their own (O’Mara-Eves *et al.*, 2013a; Zelmer, 2019; Vargas *et al.*, 2022; Silvola *et al.*, 2023). Published evidence of co-production of healthcare services with and for people with learning disabilities has mainly focussed on development of easy read resources and service evaluation surveys rather than co-production of pathway/service design (Kuper *et al.*, 2023; Anderson-Kittow *et al.*, 2024). While these approaches are valuable, they often position people with learning disabilities as consultees rather than as active partners in shaping services, and they rarely address how individuals and families navigate complex healthcare pathways in practice.

This gap is particularly salient in eye care, where access barriers for people with learning disabilities extend beyond clinical need to include communication challenges, anxiety, environmental barriers, and lack of continuity across services. In response to these challenges, the role of a ‘Vision Champion’ within learning disability healthcare professionals, who understands and promotes understanding about visual abilities and needs, has been reported upon and evidenced to improve ability to identify eyecare needs and provide more vision friendly environments (Dick *et al.*, 2015; Finlayson *et al.*, 2017). Peer to peer published work in the learning-disabled population has to date mainly focused on lifestyle/physical activity (Marks *et al.*, 2019) with one study reporting on a dental ‘ambassador’ peer advocacy model (Witton, Potterton & Smith, 2017). These studies report positive outcomes where peer to peer advocacy is implemented and suggest that this may be a feasible and effective mechanism for supporting access and satisfaction within other healthcare pathways, including eye care.

The existing evidence highlights a mismatch between policy aspirations for co-production and advocacy, and the reality of how eye care pathways are experienced by people with learning

disabilities and their families. While professional advocacy roles such as Vision Champions have demonstrated value, there remains limited evidence on models that combine professional expertise with peer-led advocacy, or that explicitly focus on promoting understanding, confidence and satisfaction across the eye care pathway. This theme therefore addresses a critical evidence gap by exploring models of eye care advocacy and pathway promotion that centre lived experience, with particular attention given to how such approaches may support people with learning disabilities and families/carers to navigate services, understand eye care needs, and feel more satisfied and empowered within the system.

First publication submitted contributing to this theme:

Framework for provision of eye care in special schools in England (2016). SeeAbility (lead Lisa Donaldson), Framework group. <https://www.rcophth.ac.uk/resources-listing/framework-for-provision-of-eye-care-in-special-schools-in-england/>

This paper, discussed in more detail in Theme 3 above, was produced in collaboration with all the eye care professional bodies, and both a family carer for, and a person with, lived experience of learning disability and complex eye care and vision needs. Both individuals attended all task and finish group meetings and commented on draft versions of the paper, as a co-produced Framework.

Second publication submitted contributing to this theme:

Karas, M., O'Brien, D., Campbell, L., Lunness, R., Kennedy, J., McGill, G., Kill, S., & Donaldson, L. (2024). The role of lived experience eye care champions in improving awareness and access to eye care services for people with learning disabilities and/or autism. British Journal of Learning Disabilities. <https://doi.org/10.1111/bld.12594>

This paper presents the first peer-reviewed, eye-care-specific account of a lived-experience “champion” model, with the Eye Care Champions (ECCs) co-authors of the publication. In 2019, the ECC role was designed to provide learning disabled peer to peer advocacy to encourage better access to eye care.

Eye Care Champions were recruited using an inclusive, values-based approach with a requirement for applicants to have lived experience of learning disability and/or autism. Recruitment processes were deliberately adapted to ensure accessibility, using plain-language materials, supported interviews and flexible assessment methods, in keeping with principles of co-production. Training

was delivered through a structured and supported programme that combined core eye health knowledge with practical advocacy and engagement skills, including understanding common eye conditions and communicating eye health messages accessibly to peers, carers and professionals. Training was provided using interactive and accessible formats and reinforced through mentoring, peer support and ongoing supervision, recognising the importance of continued development and support in sustaining confidence, wellbeing and impact over time.

The Eye Care Champions' early peer to peer work anecdotally evidenced barriers to accessing good eye care. This led to both a redesign of the LOCSU Easy Eye Care pathway (as discussed in more detail in Theme 3 above) and an evolution in the ECC role to include educating eye, health and social care providers of the importance of routine eye care for people with learning disabilities and autism. This ensures the lived experience of people with learning disabilities and/or autism becomes part of the discussion and planning process for specialist eye care pathways at both a local and national level.

Our paper (Karas *et al.*, 2024) details the role of the ECC and explores the experiences of the SeeAbility ECCs after four years in the role. We used structured interviews and thematic analysis to articulate their role in highlighting and attempting to reduce eye health inequalities. About 70% of their interactions were with professionals, planners and commissioners. The ECCs spoke of growing confidence over time and highlighted the importance of early, structured training—specifically in communication, presentations, and the healthcare landscape. Clear, unequivocal messaging, such as “*everyone should be able to access an eye test*”, was central to the role. Notably, social media was seen as effective for professional outreach but was avoided for direct peer engagement due to safeguarding concerns. Relationships with professionals were not only pragmatic but emotionally resonant. The lived experience of ECCs created a personal connection that was reported as making clinicians and planners more receptive. Employment in the ECC role offered more than advocacy impact—it also supported personal development, especially for those with limited paid work opportunities, enhancing confidence and even leading to further education or employment opportunities.

When considering transferring this model to other areas of health, it is suggested that clear calls to action (in the case of ECCs, this is the need to have an eye test) and effective clear messaging (here around the incidence of eye problems and how to access eye care) are established at the outset. (Hargreaves *et al.*, 2022) reported the successful use of similar clear unambiguous messaging on

alcohol limits and legislative alcohol controls in delivering the alcohol health champion intervention. Because the eye care sector focuses promotional activity on retail (sale of glasses and contact lenses), which can be a barrier for people with learning disabilities who often have a lower income (Emerson, 2007) a clear healthcare message is vital to improving uptake of services.

Evidence of Impact:

The results suggest the ECCs were successful in exploring and developing a network of contacts both peer and professional. Some comments from the ECCs suggest that at the outset, the building of a network could be more systematic and planned. Work has shown that experiencing social support and connectedness in health advocacy programmes is critical (Agarwal & Brydges, 2018). It can therefore be hypothesised that receiving messages from peers and/or people with lived experience to make messaging relatable and ‘personal’ is impactful and this is borne out by the reports of the ECCs.

The paper is intended to inform the future activity of eye care champions as well as support the development of other ‘health champion’ lived experience public health promotion roles. By investing in practical skills and engaging across system layers—from individual to commissioner—the ECC model demonstrates a model for equitable, effective, and scalable health promotion.

Areas for further research:

More work is needed to explore the impact of ECC interventions, including investigating if the message is having the intended outcomes of increased uptake of eye tests and change in the practice of health and social care professionals.

Theme 5 Exploring models of health care: what can eye care services learn from other fields for people with learning disabilities.

Background

Building on the need for targeted eye care pathways established in Theme 3, this theme examines how other healthcare sectors have operationalised similar principles at scale.

People with learning disabilities experience profound and persistent health inequalities, including poorer access to healthcare, higher levels of multimorbidity, and significantly reduced life expectancy compared with the general population. Many of these disparities are attributable not to the underlying impairment itself, but to health systems that are poorly adapted to meet their needs (Heslop *et al.*, 2022). In response, a range of healthcare fields outside eye care have developed targeted models designed to improve access, coordination, and patient experience for people with learning disabilities. Examining these models provides valuable insight into how eye care services might evolve to deliver more equitable and effective care.

A central concept across multiple healthcare domains is the provision of reasonable adjustments, a legal requirement under the Equality Act (HM Government, 2010). Reasonable adjustments—such as longer appointments, flexible scheduling, accessible information, and environmental adaptations—are widely recognised as essential to enabling equitable access to services for people with learning disabilities. Evidence from acute care and mental health settings demonstrates that when reasonable adjustments are proactively identified and consistently implemented, patient experience, safety, and clinical outcomes improve (Moloney, Hennessy & Doody, 2021). However, this scoping review also highlights that while the principle of reasonable adjustment is well established, there remains limited evidence on systematic implementation and outcome measurement, with practice often reliant on individual champions rather than embedded pathways. This mirrors challenges observed in eye care, where reasonable adjustments are inconsistently applied in community settings.

Another well-evidenced model is the use of learning disability liaison roles, particularly within acute hospital care. Learning Disability Liaison Nurses (LDLNs) act as system navigators and advocates, supporting communication, facilitating reasonable adjustments, advising on capacity and consent,

and coordinating care across services. Evaluations report improved communication, more person-centred care, enhanced staff confidence, and better experiences for patients and carers when liaison services are in place (Brown *et al.*, 2012; Castles *et al.*, 2014; Brown, 2020). Importantly, these roles address systemic barriers rather than relying on individuals with learning disabilities to adapt to inflexible services. The success of liaison models suggests that analogous roles could support access and continuity within eye care pathways.

Primary care offers further transferable learning through the Learning Disability Annual Health Check programme. Annual health checks have been shown to identify previously unrecognised health needs, improve uptake of preventive care, and support better engagement with services (Buszewicz *et al.*, 2014). Qualitative studies highlight that proactive, structured, and relationship-based approaches—rather than reactive models—are key to improving access and satisfaction for people with learning disabilities (Wigham *et al.*, 2022). These findings are particularly relevant to eye care, which is often episodic and reactive, and suggest potential value in more proactive, planned, and coordinated eye care reviews for this population.

Across healthcare fields, care coordination and pathway integration have emerged as critical enablers of equitable care for people with learning disabilities, especially those with multiple long-term conditions. Evidence indicates that fragmented, condition-specific pathways lead to poorer outcomes and increased burden on patients and carers, whereas coordinated models with clear roles, shared information, and continuity of relationships improve both efficiency and experience (Department for Health and Social Care, 2020). Given that adults with learning disabilities commonly have multiple co-existing conditions, eye care pathways that operate in isolation from wider health systems risk perpetuating inequities and missed opportunities for holistic care.

Collectively, these models from acute care, primary care, and mental health demonstrate that improvements in access and experience for people with learning disabilities are most effective when services adapt structurally rather than expecting individuals to conform to standard pathways. Key transferable principles include anticipatory reasonable adjustments, specialist liaison or navigator roles, proactive planned care, and integrated pathway design. This theme therefore explores how such approaches—successfully implemented elsewhere in healthcare—can inform the development of more accessible, coordinated, and person-centred eye care services for people with learning disabilities and their families.

Publication submitted contributing to this theme:

Donaldson, L., O'Brien, D., & Karas, M. (2024). A review of the evidence that people with learning disabilities experience eye health inequalities: What policies can better ensure an equal right to sight? *British Journal of Learning Disabilities*, 52(2). <https://doi.org/10.1111/bld.12573>

Having informally reviewed the evidence of eye health inequalities experienced by people with learning disabilities and autism, it became apparent that this had not previously been collated and reviewed in the context of the wider health inequalities they experience as a group. This paper (Donaldson, O'Brien & Karas, 2024) reviews published models of health care for people with learning disabilities as well as the published evidence of the eye health inequalities they experience.

Key areas of commonality with other evidence-based specialist services for people with learning disabilities were:

Specialised and Dedicated Care Pathways

Every GP annual health check could potentially, and optimally, include automatic referral into NHS-funded specialist eye care services, delivered by trained and supported community optometrists (such as the LOCSU Easy Eye Care pathway (LOCSU, 2020a) .

The education sector in the UK has evolved to a model where the majority of children with special educational needs attend mainstream schools with some additional support, whilst the 5% of children with the most complex needs (gov.uk, 2024) with an Education Health and Care Plan (EHCP) attend a special school. This educational setting provides targeted services to the children and young people with the highest levels of need. Special schools involve multi-disciplinary professional teams from across health and care to optimally address their students' complex needs. Professionals providing care and support in the special school setting include nurses, paediatricians, habilitation workers, qualified teachers for vision and multisensory impairment, speech and language therapists, occupational therapists and counsellors. The Framework for provision of eye care in special schools (Royal College of Ophthalmologists, 2016) builds into this model. The children access eye care in their familiar settings, with their specialist teaching staff, where findings can be shared with the wider multidisciplinary team around the child.

Peer-to-Peer Promotion & Lived-Experience Advocacy

The role of the lived experience learning disability Eye Care Champions (ECC) as discussed in Theme 4 builds upon models of community engagement, co-production and public health advocacy used in other areas of health and care (O'Mara-Eves *et al.*, 2013b; Hargreaves *et al.*, 2022; Vargas *et al.*, 2022) to raise awareness, support outreach, and influence commissioning and clinical practice to bridge gaps between communities and services.

Addressing Common Barriers through Adjustments and Training

Eye care services should build on the reasonable adjustments principle outlined above.

All employees of health and care providers regulated by the Care Quality Commission (CQC) are mandated by the Health and Care Act 2022 (Gov.UK, 2022) to complete the Oliver McGowan Mandatory Training in learning disability and autism (Health Education England, 2022). As primary eye care providers are not regulated by the CQC but by the General Optical Council and not the Care Quality Commission, they are excluded from this mandate, however our paper (Donaldson, O'Brien and Karas, 2024) argues that the General Optical Council should make this a requirement for all regulated professionals and employees of registered businesses. This is particularly important for non-clinical staff who may have no experience or training at all in disability awareness. See Ability and City St Georges have recently collaborated on a study (currently in writing) exploring the need for this. The Tier 1 Oliver McGowan training was offered to all practice staff with CPD points available on completion for optometrists and dispensing opticians and structured interviews and thematic analysis was completed to explore response to the training. Our findings evidence a need for training and for it to be mandated given that engagement with non-clinical staff was difficult and participation was very low.

Integration and System-Level Design

Other health areas benefit from integrated systems rather than ad hoc solutions, as demonstrated by liaison models. Eye care can learn from that by building integrated referral pathways between community optometry and hospital eye services, reducing inappropriate referrals and improving coordination such as recommended by (Pilling *et al.*, 2022).

Using Evidence-Based Policy to Drive Change

Other specialties rely on strong data and advocacy to shape policy. In eye care robust prevalence evidence for children now exists (Das *et al.*, 2010; Woodhouse *et al.*, 2014; Pilling and Outhwaite, 2017; Donaldson *et al.*, 2019) and this can be extrapolated for adults.

Policymakers have been influenced to adopt reforms such as sight and dental testing in special schools, a direct outcome of such advocacy.

The paper (Donaldson, O'Brien & Karas, 2024) brought together and helped to articulate the case for change and provided further evidence in support of the need for commissioning of targeted primary eye care services for this patient group.

Areas for further research:

A project plan is in development to replicate the task and finish group model used to produce the Framework for provision of eyecare in special schools (Royal College of Ophthalmologists, 2016) to develop a 'Framework for eye and vision care for people with a learning disability'. A co-produced paper which articulates a consensus for the necessary policy changes in (Donaldson, O'Brien and Karas, 2024), agreed by the eye care professional bodies, learning disability and sight loss charities and people with lived experience of learning disability and family carers will provide strong evidence for decision makers and commissioners.

Conclusions

This thesis presents a coherent body of research spanning 25 years, evidencing and addressing inequalities in access to eye care for two high-risk groups: children under six and people with learning disabilities. Across the included peer-reviewed publications and linked service evaluations, the work has consistently shown that unmet eye care need is not explained by low clinical need, but by structural and practical barriers: fragmented pathways after screening, inconsistent referral routes, limited awareness among professionals and families, variable workforce confidence and training, and service models that do not routinely accommodate children and adults with complex communication and sensory needs. Collectively, the thesis demonstrates that equitable eye care is both feasible and deliverable when services are designed around objective clinical methods, reasonable adjustments, and proactive support to ensure that clinical findings translate into meaningful functional benefit in learning and daily life.

Strategies used to reduce inequalities

A distinctive contribution of this programme of work is that it did not stop at documenting inequalities; it applied multiple strategies to reduce them, drawing on research evidence, implementation learning, and lived experience.

Increasing awareness was achieved through peer-reviewed evidence, professional education and guidance, and lived-experience advocacy that challenged persistent misconceptions about the feasibility of examining very young children and individuals with learning disabilities. A recurring message across the work is that objective methods (e.g., retinoscopy) and practical reasonable adjustments make eye care possible for all, and that the barriers are often systemic rather than clinical.

Influencing policy was a central mechanism of impact. Research findings were used to inform national guidance on pathways following school-entry vision screening, to support development of the LOCSU paediatric and Easy Eye Care pathways, and to influence NHS commissioning of in-school sight testing and spectacle dispensing across England. This thesis therefore evidences not only the need for change, but the translation of research into policy instruments that reshape access.

Specialist eye care pathways for these patient groups are not yet in place across England and further service evaluation is needed to make this a reality.

Influencing practice was achieved through development of clinical guidance on assessment approaches and onward referral thresholds that enable primary care clinicians to manage these patient groups more autonomously. The evaluation of in-school eye care and spectacle provision—alongside evidence of high parental and school satisfaction—supports the routine use of in-school eye care, in-school dispensing and fitting, proactive support with spectacle adaptation, and the use of practical plain-English reports that communicate visual abilities, needs and limitations to families and educators.

The enabling context of SeeAbility

A key enabling context for this programme of work has been the infrastructure and mission of SeeAbility as a learning disability charity. Organisational support facilitated research-in-action: iterative pathway design within real-world delivery environments, the evolution of the Eye Care Champion role, and a convening platform that brought together professional bodies, commissioners and people with lived experience to develop consensus frameworks. This context strengthened the applied relevance of the research and enabled the work to progress from documenting inequity to specifying delivery mechanisms that reduce it.

Methodological considerations and limitations

Methodologically, evaluating interventions within routine delivery settings strengthened real-world relevance and increased the likelihood of influencing policy and system change. This approach prioritised external validity and implementation learning, while recognising that it limits the degree to which causal attribution can be made compared with controlled designs.

Two gaps remain salient. First, adults with moderate-to-profound learning disabilities remain under-represented in the evidence base relative to special-school cohorts, and pathways to optimally meet their needs are less well explored. Second, longitudinal outcomes—including sustained spectacle wear, functional vision, educational participation, quality of life, and long-term health and social care outcomes—remain insufficiently described. As services scale, robust longitudinal and economic evaluation will be essential to secure durability and equity.

Implications for identification and recognition of visual impairment

The thesis reinforces the message that people with learning disabilities have substantially increased prevalence of both avoidable and unavoidable visual impairment, with prevalence rising further with severity of disability and in specific syndromes. This epidemiological risk profile makes proactive eye care a core equity issue rather than an optional adjunct to care.

A key interpretive contribution of the thesis is the careful treatment of low ophthalmology referral rates. In Donaldson *et al.* (2019), referrals comprised 3.1% for “medical opinion” overall (29/949), of which 1.8% were specifically referred to an ophthalmologist (17/949) and 1.3% to a GP (12/949). This finding warrants reflection because it can be misread as implying low ocular disease burden. In context, a more plausible interpretation is that appropriately adapted primary/community eye care can identify and manage a substantial proportion of need without secondary care involvement. Many visual problems in these populations are refractive or functional, and large proportions of unmet need can be addressed through refraction, spectacle provision with support, environmental adaptations, and clear communication of visual function—without recourse to ophthalmology.

Crucially, low referral rates reflect the clinical reality that much ocular pathology in special-school populations is non-progressive and already medically diagnosed (e.g., structural abnormalities, sequelae of prematurity, cerebral visual impairment), such that routine hospital follow-up is not always necessary where a suitable community alternative exists. In this sense, low ophthalmology referral rates can be an indicator of appropriate triage and proportionate care—provided that systems remain vigilant to progressive conditions and red flags.

At the same time, the grey literature highlights that people with learning disabilities face significant barriers to hospital eye services, including anxiety in unfamiliar environments, communication difficulties, reduced tolerance of procedures, and challenges navigating referral pathways. These barriers contribute to historically low uptake of both optometry and ophthalmology, particularly among adults and those with the most complex needs. This strengthens the argument that the value of specialist, learning-disability-informed primary eye care lies not in increasing referral volume, but in differentiating between conditions that require medical intervention and those that require recognition, adjustment and support within primary care. When eye care is delivered by clinicians with relevant expertise, confidence in decision-making improves and referrals become more judicious, aligning with professional guidance that emphasises “right patient, right time, right pathway,” supported by accessible adjustments.

Implications for workforce, regulation and commissioning

The thesis identifies workforce development and commissioning alignment as pivotal for sustaining equitable models. NHS commissioning guidance for special-schools eye care does not consistently align with the Framework recommendation for additional specialist training; therefore, continued promotion of structured clinician training (e.g., the City St George's/SeeAbility programme or equivalent) as a commissioning standard is important. In parallel, extending learning disability and autism training expectations across General Optical Council-regulated settings—including non-clinical staff—would align optometry with the wider NHS approach to reasonable adjustments and patient safety.

While this thesis argues that the current General Ophthalmic Services contract is insufficient to equitably meet the needs of people with learning disabilities, it includes the rationale for recognising people with learning disabilities and autism as a high-risk group with explicit entitlement to NHS sight testing, and for ensuring spectacle dispensing for vulnerable groups is delivered by appropriately regulated professionals. Finally, specialist community pathways—such as Easy Eye Care commissioned as enhanced services in practices or community hubs—should be developed alongside special-schools provision to ensure equity for children and adults not in special educational settings, enabling unified public health messaging and embedding annual eye care within learning-disability annual health checks.

Transition from child to adult services

While childhood provision is improving—particularly for special-school pupils through the introduction of a national model—adult eye care pathways remain fragmented and poorly aligned with need. Transition commonly coincides with loss of structured support, reduced parental advocacy, and wider discontinuities in health and social care, creating a predictable risk that eye care will be deprioritised. Adult services still rely heavily on self-initiated access to community optometry, and although policy attention to reasonable adjustments has increased, the mismatch between the primary care contract and the needs of this population is likely to perpetuate unmet need. As a result, transition remains a persistent point of vulnerability, and a priority for service redesign and research.

Ethical and practical considerations

Delivering eye care in familiar environments—special schools, adjusted community practices or community hubs—represents an ethical response to foreseeable barriers such as anxiety and distress in unfamiliar clinical settings. Co-production with families and people with learning disabilities strengthens acceptability and safety. As services expand, vigilance is required to avoid unintended barriers, including opt-in consent processes that depress uptake, overly complex referral rules, or digital-only communication methods that exclude households already facing inequality.

Key Successes

Developed, piloted and evaluated targeted community pathways (LOCSU post-screening diagnostic pathway; LOCSU Easy Eye Care; special-schools eye care model).

Quantified high levels of unmet need and previously undiagnosed visual deficiency, influencing pathway design and national commissioning commitments.

Demonstrated that integrated optometrist–orthoptist–dispensing models can reduce avoidable secondary-care use while improving spectacle uptake and satisfaction.

Contributed to consensus guidance and frameworks, including referral thresholds and special-schools eye care standards.

Advanced lived-experience and peer advocacy (Eye Care Champions) as a delivery and implementation mechanism.

Overall contribution and next steps

The publications presented in this thesis, together with associated dissemination activities, have contributed to the evidence base, policy landscape and practical delivery of equitable eye care for vulnerable populations. The body of work progresses from delineating unmet need to designing, evaluating and institutionalising models that are proactive, adjusted, multidisciplinary and embedded in the communities where people live and learn. Its distinctive contribution lies in specifying how inequalities can be reduced in practice—through coherent policy instruments, workforce accreditation and service delivery mechanisms that ensure clinical findings translate into functional improvements in learning and daily life.

The immediate imperative is to sustain commissioning momentum while generating longitudinal and economic evidence to secure durability and equity at scale. Realising an equal right to sight for children and for people with learning disabilities depends on scaling what is demonstrably feasible, subjecting scale-up to rigorous evaluation, and maintaining a central role for lived experience in design and governance.

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Appendix 1: Conference Presentations, Invited Lectures, Posters, Abstracts and Keynotes

1. International Association for the Scientific Study for Intellectual and Developmental Disabilities (IASSIDD) *Special Schools Eye Care; An effective model to address high levels of unmet need* (September 1, 2025) [Abstract Presentation]
2. International Association for the Scientific Study for Intellectual and Developmental Disabilities (IASSIDD) *Addressing visual impairment in people with learning disabilities: How inclusive eye health promotion programmes and primary care policy change can help achieve a more equal right to sight* (September 1, 2025) [Abstract Presentation]
3. British Congress of Optometry and Vision Science. (2024, September 12). *Parent perspectives of the special school eye care service* [Abstract presentation]. City St. George's University of London, London, England.
4. Assistive Technology and Communication Conference. (2024, October 23–24). *Vision for Even Better Communication: Understanding everyone's visual abilities and needs* [Invited keynote speech]. Mozaik Event Center, Zagreb, Croatia.
5. Breaking Barriers Congress. (2024, May 30–June 1). *Vision for Even Better Communication: Understanding everyone's visual abilities and needs* [Invited keynote speech]. World Trade Centre, Barcelona, Spain.
6. Tobii Dynavox Annual Conference. (2023). *Vision for Even Better Communication: Understanding everyone's visual abilities and needs* [Invited keynote speech]. Stockholm, Sweden.
7. Royal Society of Medicine. (2023, September 28). *Understanding vision and eye care for children with learning disabilities* [Invited lecture]. 42nd Annual General Practice and Primary Care Update, London, England.
8. Learning Disability Professional Senate. (2022, June 22). *Addressing eye health inequalities for people with learning disabilities* [Invited lecture]. Online.
9. 100% Optical. (2022, March 23). *Takeaways for Eye Care Practitioners in examining, diagnosing, and assisting those with learning difficulties and disabilities to improve outcomes for life* [Invited lecture]. Excel, London, England.

10. Royal College of General Practitioners Special Interest Group on Learning Disabilities. (2022, March 10). *Preventing sight loss and helping people with learning disabilities get better eye care* [Invited lecture]. Online.
11. Council for Disabled Children. (2021, December 6). *Children with learning disabilities and their eyesight* [Invited speaker]. Online.
12. British Congress of Optometry and Vision Science. (2021, September 7). *NHS England Special Schools Eye Care Service* [Invited keynote speaker].
13. British Academy of Childhood Disability Annual Scientific Meeting. (2020, March 13). *Providing eye care to children with disabilities: Where are we now and where do we want to get to?* [Invited lecture]. Presented with Prof. Rachel Pilling, Consultant Ophthalmologist, Bradford Teaching Hospitals NHS Foundation Trust.
14. England Vision Strategy. (2019, June 26). *People with learning disabilities—barriers, inequalities, and solutions to accessing good eye care* [Invited speaker].
15. Vision UK Conference. (2019, October 19). *The eye care needs of the special schools population* [Invited lecture]. BMA House, London, England.
16. Royal College of Ophthalmologists Congress. (2019, May 20). *The world's largest special school visual assessment programme: Lessons learnt and the "ideal" model* [Invited lecture]. Glasgow, Scotland.
17. College of Optometrists Annual Conference Optometry Tomorrow. (2019, February 23–24). *A framework for the provision of eye care in special schools* [Abstract/poster presentation].
18. College of Optometrists Annual Conference Optometry Tomorrow. (2019, February 23–24). *Parental views of an in-school eye care service for children with severe learning disabilities* [Abstract/poster presentation].
19. British Academy of Childhood Disability Annual Scientific Meeting. (2018, June 14). *A framework for the provision of eye care in special schools* [Abstract/poster presentation]. Royal College of Paediatrics and Child Health.
20. British Academy of Childhood Disability Annual Scientific Meeting. (2018, June 14). *Parental views of an in-school eye care service for children with severe learning disabilities* [Abstract/poster presentation]. Royal College of Paediatrics and Child Health.
21. 100% Optical. (2018, January 28). *Better eye care for people with learning disabilities* [Invited mainstage lecture]. Excel, London, England.

22. All Party Parliamentary Group on Eye Health and Visual Impairment. (2017, December 13). *Access to sight tests and glasses among seldom-heard groups* [Invited presentation]. Parliament, London, England.
23. British and Irish Orthoptic Society. (2017, September 13). *The SeeAbility Children in Focus Project: Our findings from testing children in their school environment* [Invited lecture]. Friend's House, London, England.
24. Royal College of Paediatrics and Child Health Special Interest Group. (2016, July 15). *Why eye care for children with learning disabilities needs reform* [Invited lecture]. London, England.
25. Clinical Council for Eye Health Commissioning. (2015, October 14). Presentation of proposal for the development of a framework for special schools eye care.

Appendix 2: Further dissemination of work

Beasley, Ian and Smith-Jayne, Ceri. (Host). (2023, September 07). The Lisa Donaldson Episode (No. 6) [Audio podcast episode]. In *The OT Podcast*. Optometry Today.

<https://www.aop.org.uk/ot/podcasts/2023/09/07/the-lisa-donaldson-episode>

BBC. (2023, Jan 16). *Something Special: Eye Test* [Television episode, Series 13:2]. Featuring a special school eye test to promote awareness that all children can access eye care.

<https://www.bbc.co.uk/iplayer/episode/m001h8fb/something-special-were-all-friends-series-13-2-eye-test>

Whittington, Richard and Richmond, Zoe (Hosts). (September 2020) with Grace McGill. Local Optical Committee Support Unit Podcast. *The refreshed “Easy Eye Care” pathway for people with learning disabilities and autism* [Podcast episode]. <https://locsu.co.uk/latest-podcast-explores-refreshed-pathway-for-people-with-learning-disabilities/>

Optometry in Practice. (2020, September 14). *Special educational needs and disabilities* [Guest editorial]. Vol 21, Issue 3. <https://www.college-optometrists.org/professional-development/college-journals/optometry-in-practice/all-oip-articles/volume-21,-issue-3/2020-09-guesteditorial-specialeducationalneedsandd>

An introduction to paediatric cerebral visual impairment. (2019, June 1). Lisa Donaldson. Optometry today (CET article) <https://www.aop.org.uk/ot/cpd/2019/05/14/an-introduction-to-paediatric-cerebral-visual-impairment/article>

Common ocular and systemic associations of learning disability. (2018, September 1). Lisa Donaldson (CET article) <https://www.aop.org.uk/ot/cpd/2018/08/16/common-ocular-and-systemic-associations-of-learning-disability/article>

The needs of patients with learning disabilities. (2017, July 7) Lisa Donaldson (CET article) <https://www.aop.org.uk/ot/cpd/2017/06/13/meeting-the-eye-care-needs-of-patients-with-learning-disabilities/article>

BBC Radio 4 (15/09/2015 *In Touch* SeeAbility's Children in Focus project exploring eye care needs in special school students with parent Alyson Farrell. <https://www.bbc.co.uk/programmes/b069vtms>

Numerous updates and presentations have been delivered to both local and national organizations, such as:

- Local Eye Health Networks
- Local Optical Committees
- Integrated Care Board Learning Disability Teams
- General Practice Learning Disability Special Interest Groups
- British and Irish Orthoptic Society Special Educational Needs Clinical Group
- NHS England Learning Disability, Dental, and Optical Team
- SEND Teams
- VIEW Conference for Teachers for the Visually Impaired
- SEND teaching conferences including NASEN National Conference

A range of Continuing Professional Development (CPD) lectures, discussion workshops, and updates have been presented to Local Optical Committees, 100% Optical, and leading eye care provider companies.

Appendix 3: Awards and Recognition

2024 Awarded Life Fellowship of College of Optometrists <https://www.college-optometrists.org/news/2024/november/college-welcomes-life-honorary-portfolio-fellows>

2021 Charity Awards Healthcare and Medical Research Award and Overall Award for Excellence awarded to SeeAbility for our special school's work <https://charityawards.co.uk/past-awards/2021-winners/>

2019 College of Optometrists Giles van Colle Research excellence award <https://www.college-optometrists.org/professional-development/research-awards-and-grants/research-excellence-awards#thegilesvancollememorialaward-11949>

Appendix 4: Parent Questionnaire from:

Donaldson, L. A., Subramanian, A., & Conway, M. L. (2018). Eye care in young children: A parent survey exploring access and barriers. *Clinical and Experimental Optometry*, 101(4), 521–526.

Dear Parents

We are a research team from City University London carrying out a survey to investigate access to eye care for families with children under 7 in conjunction with the College of Optometrists. All responses will be treated as confidential and anonymous. Your participation in this research survey is voluntary. The survey should take less than 5 minutes to complete and all completed surveys will be entered into a draw to win £100. **PLEASE RETURN FORMS ASAP TO BE ENTERED INTO THE DRAW.**

If you have any questions regarding the survey/ research please contact Lisa Donaldson on [REDACTED] or email: [REDACTED]

Please answer these questions about your child currently in reception/year 1 (if you have more than one child in reception/year 1 please complete a separate form for each child)

1. Is there a routine vision screening in your child's school? **Yes/No/Not sure**
2. Have you ever had any concerns about your child's eyes or vision? **Yes/No/Not sure**
3. Would you know how to access an eye test appropriate for your child's age if you had any concerns?
Yes/ No /Not sure
4. Do you or any of your child's close family i.e. parents, brothers or sisters have glasses, a lazy eye (amblyopia) or an eye turn? **Yes/No/Not sure**
5. Has your child ever had any kind of eye or vision test? **Yes /No/Not sure**
6. Has your child ever been refused an eye test? **Yes/No/Not sure**
7. What reason was given when your child was refused an eye test? **Yes/No/Not sure**
8. For what reasons would you consider seeking an eye examination for your child (**please tick all that apply**):

- ☐ Advised by health care provider or teacher
- ☐ Concerns about poor vision
- ☐ Concerns eyes not straight/had a turn
- ☐ Headaches
- ☐ Poor concentration/short attention span
- ☐ Poor school achievement and/or difficulties with literacy
- ☐ Complaints of double vision
- ☐ Routine check-up
- ☐ Family history
- ☐ Step-father has a squint
- ☐ Other – please state

9. Please state any possible reasons that may prevent you from taking your child for an eye test (**please tick all that apply**):

- ☐ I don't know how and/or where to arrange an appointment for an eye test
- ☐ I am worried about the cost of an eye test
- ☐ I am worried about the cost of glasses
- ☐ I think my child is too young to have an eye test
- ☐ I am worried my child doesn't yet know all the letters
- ☐ I have been told that my child is too young for an eye test
- ☐ I don't want my child to wear glasses
- ☐ I am worried my child may be given glasses he/she doesn't need
- ☐ I am worried if my child is given glasses it will make his/her eyes weaker
- ☐ Other (please state)

Please read and respond (circle) with your existing knowledge to the following statements:

10. Children can only have an eye test when they know the names of the letters

Agree Disagree Not Sure

11. Eye checks at an optician's/optometrist's are free on the NHS for children under 16

Agree Disagree Not Sure

12. Wearing glasses if you need them when under age 7 will make your eyes and vision stronger

Agree Disagree Not Sure

13. It is normal for a child aged 1–7 years to occasionally have an eye turn

Agree Disagree Not Sure

14. School vision screening tests for all eye problems

Agree Disagree Not Sure

Finally please answer the following about yourself:

15. Please state your FULL postcode_____

(This information will only be used to map services)

16. Please circle the ethnic origin you identify with:

Asian-Bangladeshi

Asian-Indian

Asian-Pakistani

Other Asian (specify_____)

Black-African

Black-Caribbean

Black Other (specify_____)

Chinese (specify_____)

White British

White Other (specify_____)

Mixed (specify_____)

Other (specify_____)

17. Do you feel comfortable speaking English? **Yes/No/Not Sure**

18. Does your child receive free school meals? **Yes/No/Not Sure**

19. What is the highest level of formal education for either parent?

- ☐ Left school before any formal exams/age 16
 - ☐ GCSEs/O levels or equivalent age 16 exams
 - ☐ AS level
 - ☐ A level /IB or age 18 equivalent exams
 - ☐ First Degree
 - ☐ Master Degree
 - ☐ PhD/Doctoral degree
 - ☐ Other? Please specify
-

We would like to contact some parents again to repeat the survey in a few months. If you are happy for us to contact you again please provide us with your contact details:

Address: _____

Telephone number: _____

Please write any other comments below (continue over the page if necessary):

Many thanks for your help in completing this survey

Appendix 5: Referral Thresholds for a community learning disability eye care pathway from Pilling et al., 2022)

Element	Referral threshold	Notes
Visual Function		
Visual Acuity/Functional Visual Assessment	Recent change in visual function Distance vision worse than 6/19* (WHO low vision definition [23]) Near vision worse than 6/19* N12 or equivalent *after adaptation to refractive correction	If the patient has previously been documented as having poor vision and there is no change in function, then referral may not be required. Visual Function may be measured using Bradford Visual Function Box [24]. No interest in an object smaller than 30 mm target at 50 cm would trigger referral Consider referral to Eye Clinic Liaison Officer, Low Vision Services and Sensory Services team Consider referral to HES for sight impairment registration where appropriate
Contrast Sensitivity (CS)		There is no specific referral threshold: however, the impact of impaired CS on a patient's ability to access visual materials is a key factor that should be included in any report or feedback and taken into consideration when considering eligibility for sight impairment certification.
Colour vision	No referral required for patients with abnormal colour vision unless known to have been acquired or associated with other change in visual function/optic disc changes.	
Refraction		
Refractive Error	Refractive error should be managed in community	Appropriate advice should be offered to patients/carers where high refractive error may be associated with complications e.g. signs of retinal detachment, angle closure glaucoma. High refractive error alone does not warrant HES referral.

Appendix 5: Referral Thresholds for a community learning disability eye care pathway from Pilling et al., 2022)

Element	Referral threshold	Notes
	Astigmatism if progressive >1D per year	Referral for keratoconus investigation may be appropriate where there is progressive astigmatism/eye rubbing
Presbyopia & Accommodation	Development of presbyopia should be considered in patients of appropriate age.	This should be managed in the community with NV specs/bifocal/varifocal [25] It should be noted that lack of accommodation is common in patients with learning disability [26–28].
Red reflex	Reduced red reflex—refer if new finding	Consider if cataract is impacting on visual function prior to referral. Consider use of Visual Symptoms in Learning Disability (VSLD) [29] to document visual function prior to referral to allow monitoring of impact on vision
Incomplete Examination	Consider referral if a specific concern is raised from the patient or carer, from a change in visual function or new ocular symptoms. Consider referral if the patient may benefit from an orthoptist assessment of vision.	LOCSU pathway [15] states that several attempts will be made by the community optometrist over a prolonged period to complete the assessment. In the absence of new symptoms or specific pathology, referral need not be made purely to complete the examination It is rare that examination under anaesthetic would be offered in the absence of specific concerns or new signs/symptoms
Lids		
Ptosis/Entropion/Ectropion	Refer if new finding or impairing patient's visual function.	Consider offering advice re interim measures for en/ectropion e.g. gel/ointment. Consider video/telephone & photo consultation with HES.
Chalazion	Refer if atypical features and/or not responding to community management measures	

Appendix 5: Referral Thresholds for a community learning disability eye care pathway from Pilling et al., 2022)

Element	Referral threshold	Notes
Trichiasis	Refer if symptomatic and evidence of corneal involvement	Consider epilation in the community
Anterior segment		
Red eyes/blepharitis	Refer if not responding to community-based measures.	Consider utilising Minor Eye Condition Scheme (MECS) [30] if symptoms are acute.
	Refer if patient photophobic and/or evidence of corneal involvement	Consider video or telephone consultation with patient/carers to discuss second level management options. Dry eye/chronic eye rubbing may require medication to manage and/or investigation for keratoconus (especially in Down's syndrome patients [31])
Microphthalmos, coloboma	Refer if associated with reduced vision eligible for sight impairment registration	Consider video or telephone consultation with patient/carers to explain condition and ensure associated medical conditions have been investigated in childhood. Consider genetic testing or counselling if patient or carer would like to explore this. Community monitoring for glaucoma may also be appropriate after discussion with HES
Corneal opacity/irregularity	Refer if previously undiagnosed or progressive.	Scissor reflex is sensitive sign for early keratoconus [31] , especially in the Down's syndrome population, and should prompt referral.
	Refer if Scissor reflex present on retinoscopy.	
Glaucoma		
Raised intraocular pressure (IOP)	Refer as per NICE guidelines [32] .	If a local referral refinement scheme is in operation, this should be utilised.
Unable to obtain IOP measurement	Referral is not necessary unless there are associated risk factors (patient over age 40 and first degree relative with POAG,	Attempts should be made to engage patients over several visits using different IOP tools (e.g. iCare) to obtain IOP.

Appendix 5: Referral Thresholds for a community learning disability eye care pathway from Pilling et al., 2022)

Element	Referral threshold	Notes
	other anterior segment abnormalities associated with raised IOP).	
Narrow angles Van Herrick	Discussion with HES to determine if additional risk factors associated with Angle Closure Glaucoma (ACG).	Unless patient high hypermetropia or other anterior segment abnormality e.g. microphthalmia, typically reasonable to offer patient and carers advice regarding signs and symptoms of ACG.
Atypical Visual Fields	Visual field deficits observed on confrontation field testing should be discussed with the HES to consider further investigation	Formal Visual Fields (e.g. Humphrey) should only be performed if there is a specific concern. Results may be difficult to interpret if the patient has problems engaging with the test procedure. Consider also referral to ECLO, Low vision or for sight impairment registration.
Fundus		
Inability to perform fundal examination due to poor engagement	If there is no change to visual function, then no referral necessary but attempts to assess fundus should be made each year.	Specific warnings about retinal detachment symptoms should be offered to patients/ carers where there is a previous history of retinopathy of prematurity or retinal detachment
Small optic disc	Refer only if not previously investigated in childhood	
Pale optic disc	Refer only if not previously documented or change in visual function	
Swollen optic disc	Refer, bearing in mind prevalence of Crowded disc appearance associated with hypermetropia	
Diabetic Retinopathy	Referral of patients with R3, R2 or M1 disease [33]	Check patient is under Diabetic Eye Screening Programme. Consider reasonable adjustments to support patient and carer to access the DESP [34, 35] .

Appendix 5: Referral Thresholds for a community learning disability eye care pathway from Pilling et al., 2022)

Element	Referral threshold	Notes
Drusen/AMD	If evidence of wet AMD, utilise local referral pathways as per NICE guidance [36] .	For dry AMD consider ECLO/Low vision referral/support organisations. Liaise with HES to determine most appropriate time/location for patient assessment, highlighting patients LD and what reasonable adjustments may be useful.
Ocular Motility		
Nystagmus	Refer if symptomatic, atypical features, vertical nystagmus or new finding.	Horizontal or manifest latent nystagmus is common in adults with learning disability. Consider discussion with HES if patient may be eligible for sight impairment registration. Refer to ECLO and low vision for support where appropriate. Note that newly acquired nystagmus will be associated with oscillopsia and the patient will be symptomatic with a change in behaviour.
Strabismus	New or changing ocular deviation/squint. Patients who express concern about their squint should be referred for consideration for ocular alignment (squint) surgery.	Adults with learning disability may assume a “relaxed” position of exotropia when not visually engaged and then realign for short periods when searching for an object. Long-standing esotropia is a common finding and may be associated with reduction in abduction [37] . Using photographs can be useful for establishing a change or new presentation. Appearance of new exotropia can indicate a loss of vision; appearance of a new esotropia may indicate blocked shunt or decompensated hydrocephalus if the deviation is larger in the distance than near.

Appendix 6: Full Survey from Donaldson *et al.* 2025

SeeAbility parent and carer survey 2023

Thank you so much for taking the time to complete this survey – it should take only 5 minutes, and your responses will help us ensure we provide the best possible service

Your details

If you wish to remain anonymous, please just tell us which school your child attends and leave the rest of this section blank

1.

Your Child's School

2.

Your Child's Name:

3.

Your child's date of birth

4.

Your Name

Please tell us whether you agree or disagree with the following statements

5. I am happy with the service my child and I receive from the SeeAbility Eye Care Service

Strongly agree

Agree

Neither agree nor disagree

Disagree

Strongly disagree

6. I would recommend the SeeAbility eye care service to other parents

Strongly agree

Agree

Neither agree nor disagree

Disagree

Strongly disagree

7. I understand more about my child's visual abilities, needs and limitations since they have been seen by the SeeAbility service?

Strongly agree

Agree

Neither agree nor disagree

Disagree

Strongly disagree

8. Please tell us where would be your first choice for your child to receive eye care

School

Hospital eye clinic

Home

An optometrists/ opticians in the high street

9. If your child needs glasses now or in the future, where would be your first choice to have them supplied and fitted?

School

High street opticians

Hospital

Other

10. I know how to contact the SeeAbility eye care team if I need to

Strongly agree

Agree

Neither agree nor disagree

Disagree

Strongly disagree

About your child's glasses if they have them

11. My child has received glasses from SeeAbility

Yes

No

12. I am happy with the glasses my child has received from SeeAbility

Strongly agree

Agree

Neither agree nor disagree

Disagree

Strongly disagree

13. My child has struggled to get used to their glasses

Strongly agree

Agree

Neither agree nor disagree

Disagree

Strongly disagree

14. The SeeAbility service has helped my child get used to wearing their glasses successfully

Strongly agree

Agree

Neither agree nor disagree

Disagree

Str

15. Please share how SeeAbility helped your child get used to their glasses or ideas for how they could have helped more with this?

Final Comments

Please note these questions are more open for your comments on the service, which we will only use anonymously in our work unless you ask us to contact you

16. Please describe the SeeAbility eye care service in 3 words

17. Please let us know if there are any ways we can improve the service or any ways we could be doing things better

18. Please provide any other comments or feedback

I would like to be contacted about my comments

YES

NO

Appendix 7: Pre-appointment Questionnaire



About My Child and their Eyes: Special Schools Eye Care Service

We need you to complete this form so that we can see your child.

If you are having difficulties completing this form, please contact us on _____ or call _____

If you have already completed this form and there has been no change in your child's eyes or your contact details, you do not need to complete it again. If there are changes, please go to the final question (37).

It is important that all children with special needs receive eye care at least once a year. If your child is already receiving regular eye care from a hospital or other provider, the Eye Care Team will not need to see them in school.

Please still let us know who is currently providing your child's eye care below. You can talk to your child's current eyecare provider about the options available to you for where they receive care in future. If at any time your child is discharged from hospital or has not had their eyes checked for more than a year, please contact _____, or call _____.

About your child and their eye care history

1. Child's Full Name *
2. Child's date of birth *
3. Child's School *
4. The name or postcode of the school site your child attends *
5. Child's full address *
6. Child's full postcode *
7. Contact email address *

8. Contact telephone number *

9. I would like my child to receive eye care from the SeeAbility team in school (we will continue to see them regularly unless you ask us not to) *

Yes

No

10. Your Child's GP Name and Address *

Yes

No

Not sure

11. Have you previously shared your child's eye care history with us *

Yes

No

Not sure

12. Has your child been seen by the SeeAbility eye care service in school in the past? *

Yes

No

Not sure

13. Is your child currently under the care of a hospital eye clinic or an Optometrist/ opticians? *

Yes

No

not sure

14. Has your child ever attended an eye clinic at the hospital?

Yes

No

not sure

it was not successful in the past (please provide further information below)

Other

15. Has your child ever had an eye test at a High Street Optician/ Optometrist? If so, please tell us when and where below

16. If your child has been under another eye care service, can the Eye Care Team contact the Hospital/ Optician/ Optometrist to access your child's eye care history?

Yes

No

What is the name of the hospital or optometrists/opticians and the date they were last seen and when they are next due to be seen?

17. If your child needs new/replacement glasses, would you like SeeAbility to supply and fit them in school?

The dispensing optician will always call you to discuss this if it's your child's first pair of glasses *

Yes

No

please call me to discuss

18. Your Full name *

19. Your relationship to the child *

20.. Are you happy for the optometrist to put drops in your child's eyes if they are needed?

Yes

No

I would like the optometrist to call to discuss before using drops.

21. Is there any significant eye care history we need to know about? (e.g. glasses, operations, patching – please provide more information below

Yes

No

22. Please tell us more about your child's previous eye care (this includes previous hospital eye care or high street opticians)

23. Do you have any concerns about your child's eyes? (e.g. do the eyes always appear straight, do they move excessively, do they squint, do they tend to shut one eye, are they sensitive to bright lights, do they complain of sore eyes or headaches etc.). If so, please provide details.

Yes

No

24. Does your child take any regular medication?

Yes

No

25. Please give details of your child's medication below

26. Please tell us any concerns you have about your child's eyes below

27. Is there a family history of any eye problems? If so, please give details.

Yes

No

Not sure

28. Please tell us about any history of eye problems in the family

29. Has your child been registered blind/ severely sighted impaired/partially sighted?

Yes

No

Not sure

30. Does your child have a preferred method of communication? If so, please let us know below.

Yes

No

Not sure

Cerebral Visual Impairment Screening

The following 5 questions help us to identify if your child's has brain-based problems in

'making sense' of their vision, a condition known as cerebral visual impairment (CVI).

31. Has your child been diagnosed previously with brain based visual impairment/ cerebral visual impairment, sometimes referred to as CVI?

Yes

No

Not sure

32. Does your child have difficulty walking downstairs?

Always

Often

Sometimes

Rarely

Never

Not applicable

33. Does your child have difficulty seeing fast-moving objects?

Never

Rarely

Sometimes

Often

Always

Not Applicable

34. Does your child have difficulty seeing something pointed out in the distance?

Never

Rarely

Sometimes

Often

Always

Not Applicable

35. Does your child have difficulty locating an item of clothing in a pile of clothes?

Never

Rarely

Sometimes

Often

Always

Not Applicable

36. Does your child find copying words or pictures time consuming and difficult?

Rarely

Sometimes

Often

Always

Not Applicable

37. If we have seen your child in the past

Please let us know any changes to your / your child's contact details (address/phone number/email/GP) below.

Have you noticed any new problems with your child's eyes, have there been any changes to their eyes or their general health/ medication or is there is anything else you need to tell us about their eyes or glasses? Please tell us more below

Appendix 8: About Your Child's Eyes Form



Special School Eye Care Service – About your child's eyes

The information in this form will help everyone to understand your child's eyesight and eye health.

Please contact the eye care team on _____ or email _____ with any enquiries. Where one is needed, this form includes your child's glasses prescription.

A copy of this report should be kept with your child's health records and support plan in school.

Child's Full Name		DOB	
Date of this test			
Recommended Date of next test			

SECTION 1 **EYE EXAMINATION DETAILS**

Where did the test take place?	
Who was present?	
What was already known about the eyes and vision?	
Did anyone have any questions or concerns about the eyes and vision?	

Section 2 **SUMMARY & ACTIONS**

About Your Child's Eyes Summary

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ACTIONS

Are glasses needed? (see Section 2)	
There is a problem with focussing accuracy (accommodation)	
Is the child/young person eligible for certification as visually impaired?	
If Yes, what are next steps?	
Is any action from the child/young person's GP required?	
If Yes, what are next steps?	
Does the child/young person need to be referred to another specialist?	
If Yes, what are next steps?	
Are modifications to classroom/schoolwork needed?	
Further information:	
Should the ECHP include information about vision needs?	
Further information:	

GLASSES PRESCRIPTION

R I G H T	Sph	Cyl	Axis		Sph	Cyl	Axis	L E F T
				DIST				
				NEAR				

When and how should these glasses be used? (e.g. distance vision, close work, etc)	
---	--

Unless you have requested otherwise, we will supply, fit and repair your child's glasses in school without charge. If you have any queries, please contact:

Eye Care Team contact:	
-------------------------------	--

For information on how to help your child get used to wearing their glasses, please see the resources at the SeeAbility website [here](#).

SECTION 3

RESULTS OF THE VISION TESTS WE DID TODAY

Visual acuity is how well a person sees black on white detail with glasses if needed.

Vision is how well a person sees black on white detail without glasses.

We were able to measure vision/visual acuity:		
- Vision/visual acuity results for distance vision		
- Vision/visual acuity results for near vision		
We have included examples of what your child should easily see More examples can be found at here .	Y	N

Binocular vision and eye movements – this is how well eyes work together

There is a problem with this	
Further information:	

Visual field – this is how well a person can see things to the side of their central vision

There is a problem with this	
-------------------------------------	--

Further information:	
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Contrast sensitivity – this is how well objects are seen against similarly coloured backgrounds

There is a problem with this	
Further information:	

Evidence of Cerebral Visual Impairment / Visual Processing difficulties – this is when there are visual difficulties caused by problems interpreting visual information in the brain, rather than the eyes

Evidence of Visual Processing difficulties	
Further Information:	

SECTION 4 **RESULTS OF THE EYE HEALTH CHECK**

Findings from health checks of the inside and outside of the eyes	
Does the child need to be referred to another specialist?	
If Yes, what are next steps?	
Nature of referral	

SECTION 5 **TECHINICAL DETAILS FOR OTHER HEALTH PROFESSIONALS**

Vision/Visual Acuity and Test Used	
Refractive Error	
Accommodative Function	
OMB and Motility/Eye Movement Control	
Contrast Sensitivity	
Visual Fields	

Eye Health Exam	
Visual processing	
Other Findings	

SECTION 6
EYE CARE TEAM ASSESSORS

Name of Optometrist (Eye Test)	
Name of Dispensing Optician (Glasses)	
Email	
Telephone	