



Children  
in focus  
campaign

# An equal right to sight

Why eye care for children  
with learning disabilities needs reform



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**Cover photo:** Nathaniel. No-one knew how much 15 year old Nathaniel needed glasses until SeeAbility visited his special school and discovered he was extremely short sighted. Without glasses Nathaniel's world is limited to just a few centimetres in front of his face and everything else is a blur. Now whenever he sees a teacher or the SeeAbility team Nathaniel will give two thumbs up and point to his new glasses.

# Summary

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SeeAbility is calling for a national plan to meet the eye care needs of children with learning disabilities in England. As a start, we recommend the government and the NHS properly fund specialist sight tests<sup>1</sup> and glasses dispensing in all special schools.

SeeAbility's Children in Focus Campaign<sup>2</sup> is providing sight tests and glasses in a number of special schools in the London area. We found that 37% of children we sight tested had no history of eye care<sup>3</sup> and that we were giving many children, some of whom were teenagers, their first ever sight test or pair of glasses.

If this is replicated across the country then thousands of children with learning disabilities are not accessing their right to a free NHS sight test<sup>4</sup>, despite the high risk of sight problems and eye disorders in this growing group of children. Children with learning disabilities are 28 times more likely to have a serious sight problem than other children<sup>5</sup>, but are less likely to be able to communicate their concerns to parents/carers should any problems develop.

This is putting some children's sight at risk because timely tests can pick up problems early before too much vision is lost. For some children, not having a pair of glasses is impeding their ability to make sense of their world and acquire skills. What is more, identification of sight problems is often symptom led and behaviour may be wrongly attributed to the diagnosis of learning disability, rather than a sight problem (known as 'diagnostic overshadowing').

Our investigation has found that, despite good work by many eye care professionals to support children with learning disabilities, there is no failsafe system to ensure all children in this high risk group receive any regular checks on their eyesight or wear the glasses they need. For some children the only regular checks they get are in a hospital eye clinic due to the lack of a community based alternative. Other children are discharged from or lost to hospital eye clinic follow up and then cannot access community based care.

There is a legal duty across the NHS to address health inequalities, but the current system appears to exacerbate them. Our report finds:

- Insufficient vision screening to pick up issues early on – school entry vision screening is a 'postcode lottery' and is often not the comprehensive test that children with learning disabilities need.

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<sup>1</sup> 'Specialist sight test' has no legal meaning but describes the model of service SeeAbility has been piloting in special schools.

<sup>2</sup> See [www.seeability.org/childreninfocus](http://www.seeability.org/childreninfocus) for more about our work in special schools.

<sup>3</sup> Although all children will have their eyes examined as a baby or in early years, this will not be as thorough as a sight test. We asked parents if their child had any history of eye care at a hospital eye clinic, or at an optician.

<sup>4</sup> The NHS funded sight test is free to children and young people under the age of 19 in full time education.

<sup>5</sup> The estimated prevalence of visual impairment is 0.2% of the general population of children (Vision 2020, 2015) compared with an estimated prevalence of 5.66% amongst children with learning disabilities (Emerson and Robertson, 2011). The estimated prevalence of visual impairment among people with learning disabilities in the UK).

- Fragmented pathways of care and communication – leading to children not wearing the glasses prescribed for them, or all-important information on the child’s visual needs not being shared across health and special education.
- A rigid primary eye care contract for sight testing services and glasses – there is little customisation for groups with specific needs, such as children with learning disabilities.
- Inadequate funding – the government applies a flat rate payment of £21.31 for sight tests – including those in special schools. This is widely acknowledged to only partly meet the cost of a ‘regular’ high street sight test, let alone the type of approach and adjustments a child with learning disabilities will need.
- Eye care low on child public health priorities – so much so that the government and NHS collect no data on the number of children with disabilities getting sight tests, eye care or vision screening.

## Recommendations

We are calling on the government and NHS England to work together to properly fund specialist sight tests and glasses dispensing in all special schools in England. This would offer the ‘right care, at the right time and in the right place’ to around 100,000 children who will (by the nature of needing to attend a special school) have some of the most complex needs or disabilities. Such a plan is in development in Wales.

SeeAbility believes it should be a matter of national policy for children in special schools:

- To be offered a comprehensive specialist sight test when they first start at school (which we recommend is a joint optometric and orthoptic assessment).
- To be offered an annual specialist sight test (or more often if necessary) performed in the familiar surroundings of their special school.
- To have their glasses fitted and be supported to get used to them, within their special school.
- To have their test results explained to them, their families and teachers, as well as their health professionals, throughout their school life and in transition to adulthood.

SeeAbility’s work in special schools has shown that sight testing in a safe, familiar and convenient environment by appropriately trained professionals helps a child co-operate with a sight test, gain the benefits of wearing glasses and participate in school. This is an opt in service, yet uptake has been as high as 80% and the service has been fully supported by parents/carers, who are not having to take their child out of school and attend appointments in unfamiliar places. Schools taking part are getting the information they also need on a child’s vision.

This arrangement needs investment – we estimate the ordinary £21.31 NHS payment to optometrists for a sight test is only a quarter of what it takes to deliver a sight test in special schools. But there are risks of much higher costs being borne by health and social care if sight issues are not addressed and there is unnecessary pressure on hospital eye clinics. It is a small price to pay for inequalities to be addressed, legal duties to be met, and for the government and NHS England to improve care for children with learning disabilities.

This would be a first major step forward but other reforms are needed. We are also calling for a national plan to improve eye care for all children with learning disabilities. This should aim to:

- raise awareness of the high risks of sight problems they face amongst parents/carers, health professionals and those in the special educational needs sector;
- improve access to mainstream services and vision screening for children not at special schools;
- enable data collection on access to eye care and the outcomes children with learning disabilities experience; and
- ensure eye care and vision information is a key part of the child's special educational needs plan, and is shared appropriately between health and education.

# An equal right to sight

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**“Every child in this country has the right to a free eye test. Why is it then that children with complex needs are not accessing those free eye tests? We need to look at these things in depth and change it for the better, because hundreds, thousands of children are missing out and they are the most vulnerable in our society. And that has got to be wrong.”**

**Kay Charles, Headteacher, The Village School, a special school in North London**

## Introduction

Sight is a critical sense for everyone. All children and their families/carers need to be aware of the importance of good eye health, including the need for regular sight tests. The visual system is developing rapidly in the early years and then into adulthood.

Some treatable problems such as certain squints, long and short sightedness or astigmatism can lead to lifelong poor vision if left untreated. If amblyopia (lazy eye) is not corrected by prescribing glasses or patching, the risk of bilateral visual impairment in later life nearly doubles.<sup>6</sup>

No national data exists on numbers of children with learning disabilities and sight problems. However in a study commissioned by SeeAbility and RNIB it was estimated that over 23,000 children and young people with learning disabilities will have serious sight problems, and over 190,000 children with learning disabilities will have some problem with their vision.<sup>7</sup>

It was also estimated that 5.66% of children with learning disabilities will have visual impairment or blindness, and a high percentage will have refractive error of some type (where the eye cannot clearly focus and glasses are needed). With visual impairment and blindness relatively rare in the general population of children, this means children with learning disabilities are 28 times more likely to have a serious sight problem.<sup>8</sup>

The high prevalence of reduced visual potential in children with learning disabilities may be due to cerebral visual impairment (vision processing in the brain), optic atrophy (damage to the optic nerve), high refractive error (astigmatism, short or long sightedness), amblyopia (reduced vision), strabismus (squint/eye turn), cataracts (clouding of the lens in the eye), nystagmus (involuntary eye movements), poor eye movement control, keratoconus (progressive changes to the shape of

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<sup>6</sup> Van Leeuwen, R. et al. “Risk of bilateral visual impairment in individuals with amblyopia: the Rotterdam study.” *Br. J. Ophthalmol.* 91, 1450–1451 (2007).

<sup>7</sup> Emerson and Robertson, 2011. The estimated prevalence of visual impairment among people with learning disabilities in the UK.

<sup>8</sup> The estimated prevalence of visual impairment is 0.2% of the general population of children (Vision 2020, 2015, Key facts about vision in children and young people) compared with an estimated prevalence of 5.66% amongst children with learning disabilities from the Emerson et al study above.

the eye's outermost layer) or developmental abnormalities of the eye. Where certain conditions limit a child's sight, it will mean that even with glasses their vision is reduced.

There is evidence that the more profound and complex the learning disability, the greater the visual impairment.<sup>9</sup> Certain conditions, such as Down's Syndrome, also make it more likely that children will experience sight problems or eye health disorders. The incidence of visual problems is also growing as this group of children grows, possibly due to the increased survival rate of pre-term and low birth weight babies, who have a higher risk of visual problems and disability.<sup>10</sup>

Recent UK research has also focussed attention on the sight problems and eye health of children in special schools. These children will, by the nature of having to attend a special school, have some of the most complex needs or disabilities.

In a study in Wales of 5 special schools<sup>11</sup>, 47% of pupils had at least one eye health issue – such as retinal abnormalities or cataracts. Nearly a quarter had a squint. In a study in Glasgow<sup>12</sup>, 12% of pupils had low vision or blindness and nearly one in five (17%) had a squint.

Both studies indicated around half of pupils needed glasses to correct refractive error.

There is one Canadian research study from the 1980s<sup>13</sup> that attempted to actually measure outcomes for children with learning disabilities when glasses were worn. Vision was tested and glasses were supplied, then teachers and supporters were asked to observe changes in behaviour of children once they had their glasses. There were significant improvements seen in the children – for example frequency of challenging behaviour decreased, and motor skills, posture and walking ability improved. These changes were most evident in the youngest age group.

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<sup>9</sup> Van Splunder et al. "Prevalence of visual impairment in adults with intellectual disabilities in the Netherlands: cross sectional study." *Eye* (2006) 20, 1004-1010

<sup>10</sup> Salt, A and Sargent, J (2014) "Common visual problems in children with disability". *Archives of Disease in Childhood*. 08/2014 99(12).

<sup>11</sup> Woodhouse M., Ryan B., et al. (2012). "A Clear Vision: Eye care for children and young people in special schools in Wales." Cardiff University and RNIB Cymru.

<sup>12</sup> Das M., Spowart K., et al. (2010). "Evidence that children with special needs all require visual assessment." *Archives of Disease in Childhood* 95(11): 888-892.

<sup>13</sup> Bader, et al (1980). *American Journal of Optometry and Physiological Optics* Vol.57 No.7.

# SeeAbility's Children in Focus Campaign

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SeeAbility's Children in Focus Campaign is using experienced optometrists and orthoptists and a dispensing optician to deliver specialist sight testing<sup>14</sup> and spectacle dispensing and fitting in a number of special schools in the London area.

Our team has experience of working with children with complex needs and has links with local hospital-based orthoptists and ophthalmologists (eye doctors) who are able to provide assistance and advice and take onward referrals where necessary. The team also works closely with parents/carers and school staff to share results. These services, along with some of the specialist testing equipment, may not be available in most high street opticians.

For some children the benefit of the service comes from the reassurance of a sight test in the familiar and convenient environment of school. Testing in schools allows us to revisit a test easily if a child becomes stressed and is only able to complete a test in more manageable sections (i.e. carrying out different parts of the test at different times, or even on different days). Even if no vision or eye health related issues are identified, it may be the first time a child has ever felt able to co-operate with a sight test. For other children the benefit comes from the identification of treatable sight or eye health issues.

Problems with visual processing in the brain rather than the eye (cerebral visual impairment) will involve an assessment of how the child reacts to the world around them. This is not a subject covered by a typical sight test, which concentrates on the integrity of structures within the eye and its ability to focus. Where possible, SeeAbility's service has used a set of questions<sup>15</sup> to probe for visual difficulties which may indicate cerebral visual impairment, and if so, this information is passed on to the school's Qualified Teacher of Children and Young People with Visual Impairment (QTVI).

Even where a child's sight problems cannot be remedied with glasses (such as cases of cerebral visual impairment) or a child is unable to tolerate glasses, once it is understood what the child can see, strategies can be developed for school and home.

SeeAbility has witnessed many positive outcomes where children have had their sight tested, glasses supplied, or strategies developed to help them at school and home. An evaluation of the first year of work in four London special schools can be found on our website. Further service evaluation is also planned by SeeAbility to confirm a range of outcomes in the Children in Focus Campaign.

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<sup>14</sup> 'Specialist sight testing' has no legal meaning but describes the model of service SeeAbility has been piloting in special schools.

<sup>15</sup> Lueck and Dutton (2015). Vision and the Brain: Understanding Cerebral Visual Impairment in Children.

<sup>16</sup> See [www.seeability.org/childreninfocus](http://www.seeability.org/childreninfocus) in particular our annual report for more detail of our first year of sight testing.

# Case study: Lana

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Lana is 9 years old and has profound learning disabilities. She cannot mobilise or speak, and uses a wheelchair. She only communicates with her eyes, so clear vision is vital for her. Without glasses Lana's vision is blurred.

SeeAbility visited Lana in her special school and gave her a specialist sight test. Just by shining a light in Lana's eye and assessing how it reflects off her retina, optometrist Lisa was able to judge the strength of spectacles Lana needs, even if Lana couldn't tell her.

The method is called 'retinoscopy' and Lisa explains: "We were able to test Lana even though she doesn't talk. She loves lights and mirrors and with the help of her teaching assistant we reassured her throughout the test.

It showed that she has a small squint, which is mainly controlled when she wears her glasses."



*You can see the joy on her face. This is an incredible step for Lana.*

With her newly prescribed glasses Lana can communicate using Eye Gaze technology, which tracks where Lana's eyes are looking so she can move the mouse pointer around. For the first time in her life she can make choices and express her preferences – and mum and teachers have really seen a difference.

# Current public health policy on eye care for children

The Public Health Outcomes Framework<sup>17</sup> recognises that more needs to be done to prevent avoidable sight loss and to reduce health expenditure. A key cause of avoidable sight loss is uncorrected refractive error – severe uncorrected refractive error has been said to account for over 50 per cent of avoidable sight loss.<sup>18</sup> Increasing uptake of sight tests and provision of glasses amongst children at high risk of refractive error can help address this. The results of a sight test may also lead to much needed certification and registration for additional support.<sup>19</sup>

The current public health interventions designed to support eye care in children with disabilities are described below:

In England every child and young person under the age of 19 in full time education has the right to a free NHS sight test.<sup>20</sup> For those under 16 a Department of Health memorandum recommends a minimum interval of a year between sight tests, but this can be more frequent if clinically justified.<sup>21</sup> The sight test and glasses vouchers are funded by NHS England at rates set by the Department of Health.

Clinical recommendations on children's health are set out in the Hall Report 'Health for all Children'.<sup>22</sup> This recommends that children of any age with suspected visual deficits, a significant family history or any neurological or disabling condition, should be routinely referred for a visual assessment. More targeted clinical surveillance of children with neurodevelopmental impairments is also endorsed by the Royal College of Ophthalmologists.<sup>23</sup>

Children with disabilities under the care of paediatricians may therefore be referred to an ophthalmologist or other eye care professional and may be accessing sight tests in the hospital or a community clinic environment.

The Hall Report also recommended that 'screening for visual impairment between 4 and 5 years of age should be offered by an orthoptic-led service'. Orthoptists investigate, diagnose and treat defects of binocular vision and abnormalities of eye movement. The UK National Screening Committee later adopted the recommendation.

<sup>17</sup> Department of Health (2012). Public Health Outcomes Framework 2013-2016.

<sup>18</sup> RNIB (2014). Sight loss: a public health priority.

<sup>19</sup> RNIB (2015). Ensuring support: Certification and Registration in children and young people with vision impairment in England.

<sup>20</sup> The Stationery Office. The Primary Ophthalmic Services Regulations 2008.

<sup>21</sup> Department of Health, Association of Optometrists, Federation of Ophthalmic and Dispensing Opticians, 2002. Memorandum of Understanding Frequency of GOS sight tests.

<sup>22</sup> Hall and Elliman (2008). Health for all children: Revised fourth edition. Oxford, Oxford University Press.

<sup>23</sup> Clarke M (2012). Ophthalmic Services for Children. The Royal College of Ophthalmologists: Ophthalmic Services Guidance.

This led to the development, within the Healthy Child Programme launched in 2008 by the Department of Health and Department of Education, of vision screening within the 'school entry health check' for 4-5 year olds. A vision screen is not a full eye examination, so a fail will lead on to referral to an appropriate eye care professional. This school entry health check also includes a check on hearing, height and weight and is commissioned by local authorities with responsibilities for public health. As an opt-out programme, it is designed to maximise participation.

If serious sight problems are detected, there are also certification and registration processes for visual impairment. These processes provide eligibility for greater support for a child in education, social care and through the welfare system – support which can help prevent needs from escalating.

# Current policy to improve health of people with learning disabilities

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People with learning disabilities have poorer health than their non-disabled peers, differences that are, to an extent, avoidable. These health inequalities start early in life and in many cases result from barriers faced in accessing timely, appropriate and effective health care. There are still cases of discriminatory attitudes.<sup>24</sup>

This has led in recent years to both national and local initiatives and strategies to put things right. Most recently, the NHS England Business Plan<sup>25</sup> aims to transform care for people with learning disabilities and redesign care pathways so that systems prevent needs from escalating. A further area of reform has been the Children and Families Act 2014, which aims to improve outcomes for children with special educational needs by developing integrated plans to support a child's health, education and care needs.

There are also legal duties which healthcare bodies must abide by. NHS England and Clinical Commissioning Groups are under duties in the Health and Social Care Act 2012 to have regard to the need to reduce inequalities between patients in terms of both access and outcomes (a similar duty applies to the Secretary of State for Health). These duties build on the binding requirements on public bodies under the Equality Act 2010 to eliminate discrimination, remove or minimise disadvantages and take steps to meet the needs of disabled people.

There has never been a national government or NHS England plan to tackle the eye care needs of people with learning disabilities – despite being a group with such a high risk of sight loss. In 2014 NHS England issued a 'call to action' consultation in order to stimulate debate on how to tackle health inequalities with regard to access to eye care services and outcomes<sup>26</sup>, but no action plan has been forthcoming.

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<sup>24</sup> Improving Health and Lives (2011). Health Inequalities & People with Learning Disabilities in the UK.

<sup>25</sup> NHS England (2015). Building the NHS of the Five Year Forward View – NHS England Business Plan 2015/16.

<sup>26</sup> NHS England (2014). Improving eye health and reducing sight loss – a call to action.

# Are children with learning disabilities accessing eye care?

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Numbers of children accessing sight tests overall is growing, but still only 21.4% of eligible children in the general population in 2014/15<sup>27</sup> exercised their right to a sight test and it is unknown how many of these children have disabilities (whether learning or other disabilities). Despite the higher risk of sight loss, any data we have relies upon findings of projects with children with learning disabilities.

SeeAbility's evaluation of our first year of service for the Children in Focus Campaign<sup>28</sup> found that:

- Nearly four in ten (37%) pupils had no history of eye care.
- If children under the care of hospital eye clinics were excluded from the figures, then this rose to 51% of children who had never had a sight test in a community optometry practice.
- Three quarters of pupils who had been under the care of hospital eye clinics had no history of follow up sight tests in the community once discharged.
- A third of pupils needed either a new glasses prescription or glasses for the first time.
- 37 of 147 pupils (25.2%) had what the World Health Organisation would classify as 'low vision' in their habitual state. Of these, 13 had not been seen by the hospital eye service and 12 had no previous eye care of any form.

In a similar study in Wales in 5 special schools, more than one third of pupils had never had a sight test. In addition, 53% of pupils needed glasses but only 30% had previously had them prescribed.<sup>29</sup>

Soon to be published results of a project in Bradford's special schools delivering visual assessments to nearly 200 children show that 42 were referred to hospital eye clinics for further investigation, 29 were prescribed or re-prescribed spectacles, 8 were offered a certification/ registration of visual impairment and 5 were referred to the learning support team for visual impairment.<sup>30</sup>

Recent research by RNIB also indicates children with complex needs and who are eligible are not always being referred for a Certificate of Visual Impairment (CVI) that would help them access services to support them in social care, welfare and education.<sup>31</sup>

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<sup>27</sup> Health and Social Care Information Centre (2015). General Ophthalmic Services, Activity Statistics: England, 2014-15.

<sup>28</sup> SeeAbility (2015) "Children in Focus Campaign, the story so far", research report.

[www.seeability.org/childreninfocus](http://www.seeability.org/childreninfocus)

<sup>29</sup> Woodhouse, M., Ryan, B. et al. (2012). "A Clear Vision: Eye care for children and young people in special schools in Wales." Welsh Government, Cardiff University and RNIB Cymru.

<sup>30</sup> For more details, contact Rachel Pilling, Consultant Ophthalmologist, Bradford Teaching Hospitals NHS Foundation Trust.

<sup>31</sup> Boyce, T (2015). Ensuring Support: Certification and Registration in Children and Young People with Vision Impairment in England. RNIB.

# Practical barriers

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There are practical barriers for children who have complex needs in accessing sight tests. Parents/carers often report difficulties such as travel to appointments; time out of school; their child becoming distressed or challenging in unfamiliar environments; and fear of not keeping an appointment.

For parents and carers of children with disabilities, identifying that a child has a sight problem can also be compounded if a child is unable to self-identify or communicate they have a problem with their vision. Identification of sight problems is often symptom led<sup>32</sup> and behaviour may be wrongly attributed to the diagnosis of a learning disability, rather than a sight problem (known as 'diagnostic overshadowing').

In the SeeAbility project, some parents/carers said that they were not aware of the importance of sight tests and had thought that a sight test had to involve reading letters off a chart and so would not be available to their child. Understandably, some parents/carers were overwhelmed with medical appointments and the care of their child – for some, a sight test was not on their list of priorities. Parental/carer burden can be very high when supporting a child with complex needs.

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<sup>32</sup> Leamon, S. et al (2014). "Improving access to optometry services for people at risk of preventable sight loss: a qualitative study in five UK locations." *Journal of Public Health*. 1–7.

# Case studies: the benefits of sight testing in school

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The following cases are from the SeeAbility project, although names have been changed in most cases, and illustrate just why school sight testing is so helpful.

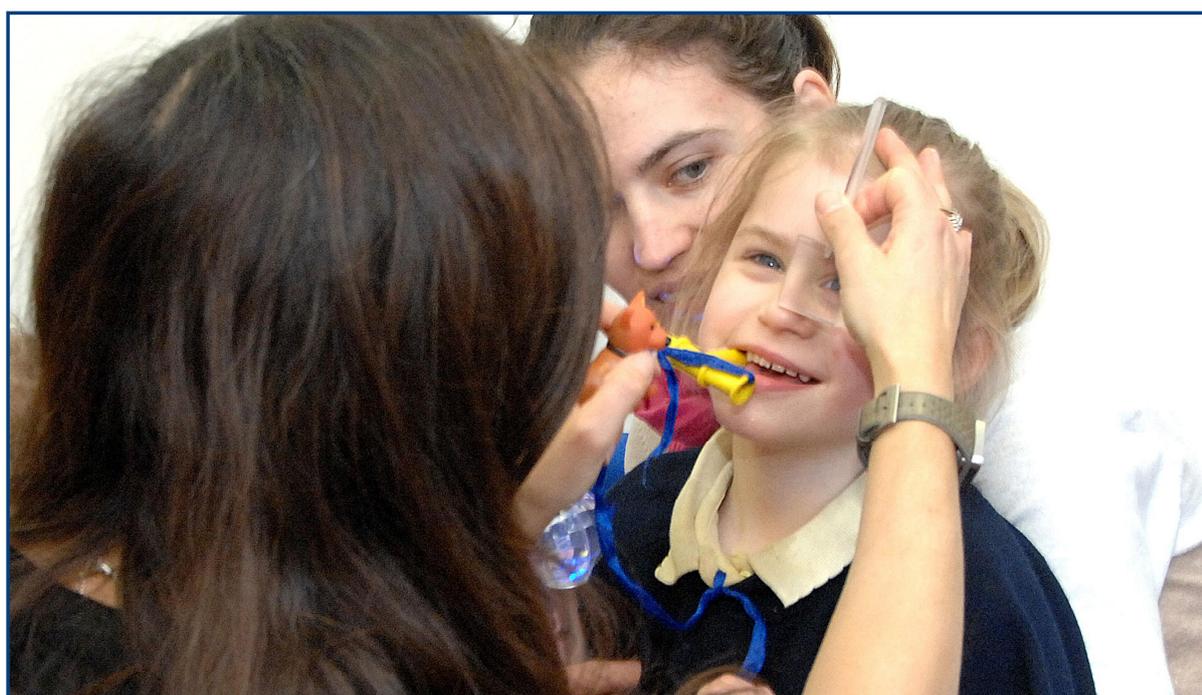
- Nasir has Down's Syndrome and an obvious squint. SeeAbility gave him his first sight test and glasses at seven – on his first encounter with optometrist Lisa he kicked her but familiarisation visits with Lisa soon helped.



*Nasir can't go to a high street optical practice because he gets upset.*

- Elise is a wheelchair user who has complex needs, is PEG fed and has difficulty breathing. A sight test in school meant she did not have to miss a school day for yet another medical appointment.
- Liam has a high level of short sightedness but had refused to wear glasses from his hospital eye clinic and attend any more hospital appointments. SeeAbility sight tested him in his classroom, provided him with glasses he chose himself and helped him get used to them. He is now wearing them for increasing periods of time every day and his behaviour and engagement in the classroom has really improved.

- Darren was discharged from the hospital eye clinic but had not gone on to have a sight test for five years. He has cerebral palsy, is a wheelchair user and after his sight test with SeeAbility was prescribed glasses.
- Jamie is autistic and his behaviour can be very challenging. He was given a strong prescription for his glasses at seven years old.
- Raju has great difficulty communicating and is a wheelchair user. The SeeAbility sight test identified previously undiagnosed underlying pathology of cataracts linked to his syndrome. This is now being treated at hospital.
- Edward gets so distressed going to hospital eye clinics he now refuses to go. SeeAbility was able to give his sight test and prescribe glasses at school.
- Catarina is autistic and non verbal. She could not cope in the school sight testing room but was able to have a sight test in her classroom. SeeAbility prescribed her glasses.
- Falak is autistic, highly anxious and has no speech. Falak needed two teaching assistants and his teacher with him to help calm his anxiety at his sight test. SeeAbility gave him his first sight test at age fourteen. Luckily there were no issues with his eyesight.
- Four year old Estera has a genetic disorder which means that she is non-verbal and hyperactive. Estera moves around alot, but optometrist Lisa has been able to test her sight and keep her interest by singing nursery rhymes, using school toys and a comfortable sofa in a school room. This has helped Estera stay still long enough to have a light shone in each eye to look at her eye health and for her eye movement to be assessed. Estera is long sighted.



*Estera needs an optometrist to adapt to her needs.*

# System barriers

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These cases show that even if there were to be a programme of raised awareness and practical actions to improve access to hospital/community eye clinics or high street opticians, there would still be many barriers for children in getting a sight test.

There remains no failsafe system to ensure all children in this high risk group receive any regular checks on their eyesight or wear the glasses they need. Indeed the current system appears to exacerbate inequalities. Our investigation has found:

- **Insufficient vision screening to pick up issues early on**

As highlighted on page 11, there is a targeted public health programme of school entry age (4 – 5 years old) vision screening in mainstream schools. However, both the British and Irish Orthoptic Society and College of Optometrists have found this to be a ‘postcode lottery’. Pressures on funding also impact on the availability of orthoptists to lead the programme of work.<sup>33</sup> Parameters are set locally regarding who is trained by orthoptists to perform the screening (which may be nursery nurses, school nurses or teaching staff).

The mixed picture extends to special schools which again experience variable funding. A full survey is due for publication by the British and Irish Orthoptic Society but confirms there are some areas of England with no eye health care within the special school setting, meaning a large percentage of children in special schools have never had an eye assessment. Yet in other areas specialist orthoptists are providing more comprehensive coverage, often with other eye care professionals and not just at school entry.

- **Fragmented pathways of care and communication**

Pathways of care break down if follow up appointments are not attended, or children are not picking up glasses that have been prescribed or wearing them – probably because of the barriers that parents/supporters report. Communications from practices or clinicians can be confusing and sight testing terminology unhelpful.

This fragmentation can be exacerbated by the way that NHS communication systems work. For example in the SeeAbility service there have been complications feeding in results of our sight testing with the children to secondary care because we have not had a ‘nhs.mail’ email address.

Onward communication from eye health professionals to teachers can be very difficult too, sometimes due to concerns about the sharing of health information. Awareness of significant refractive error or simply the need to wear glasses has been shown to be lacking in plans to support children with special educational needs, risking the wrong conclusions to be drawn as to why a child has difficulties with school tasks.<sup>34</sup>

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<sup>33</sup> De Zoete (2007). Children’s Eye Health, a report on vision screening for children.

<sup>34</sup> Little J, Saunders K (2015). “A lack of vision: evidence for poor communication of visual problems and support needs in education statements/plans for children with SEN.” Public Health 129. 143-148.

- **A rigid primary eye care contract with little customisation for children with learning disabilities**

The General Ophthalmic Services Contract (GOS) needs modernising to reflect the needs of children with disabilities. It is telling that the contract as drafted lists day centres and residential care – both services for adults with disabilities – as settings where mobile sight tests can take place outside those which can be offered in the person’s home. Even if home visits are available, the government is unaware if children with disabilities actually benefit from them.<sup>35</sup> Under pressure, the government and the NHS have recently taken the welcome step of accepting that GOS funded sight tests can take place in special schools, and should be congratulated for this.<sup>36</sup>

But issues remain: a child with a learning disability may regularly break their glasses, or need flexible frames, but rules for getting a spare pair of glasses or repairs are complex.<sup>37</sup> Currently GOS does not provide vouchers for frames for special facial characteristics that are common in some children with learning disabilities. And some of the testing required under GOS – shining a light in a child’s eye, or eye drops to dilate the eye, may be too intrusive and distressing for some children, meaning a practitioner may not be paid.

- **Inadequate funding**

The fact that GOS exists as a national budget is welcome. But the GOS contract payment to operate in special schools is £21.31 per sight test – which is the ‘day centre’ rate for mobile sight tests and the same as the fee paid to high street practices.

This fee is potentially only half of the actual cost of a regular sight test in a high street optician.<sup>38</sup> Certainly from our experience of the first year of our sight testing project, SeeAbility estimates that it costs circa £85 to undertake a specialist sight test in a special school because of the additional time, support, equipment and repeat visits a child may need to prepare for and complete a sight test.

With GOS funding strictly limited, local commissioners have had to find the financial incentives to address health inequalities by paying for enhanced services<sup>39</sup>, often on top of the GOS fee. An enhanced pathway for adults and young people with learning disabilities operates in a number of areas, providing a reasonably adjusted service of helpful preparation, extended time at the sight test and feedback afterwards.<sup>40</sup> The problem with this approach is that it still leaves inequalities where the pathway is not in operation.

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<sup>35</sup> See Hansard 5 March 2015 <http://www.parliament.uk/business/publications/written-questions-answers-statements/written-question/Commons/2015-02-26/225539>

<sup>36</sup> See Hansard 19 March 2015 <http://www.parliament.uk/business/publications/written-questions-answers-statements/written-question/Commons/2015-03-16/227618>

<sup>37</sup> The National Health Service (Optical Charges and Payments) Regulations 2013

<sup>38</sup> Shickle, D et al. “Why is the General Ophthalmic Services (GOS) Contract that underpins primary eye care in the UK contrary to the public health interest?” BJO Online First. 1 October 2014.

<sup>39</sup> See Local Optical Committee Support Unit Community Services Pathways <http://www.locsu.co.uk/community-services-pathways/>

<sup>40</sup> See the LOCSU learning disabilities pathway <http://www.locsu.co.uk/community-services-pathways/community-eye-care-pathway-for-adults-and-young-pe>

- **Eye care low on child public health priorities**

Compared to obesity or dental care, vision appears to be less of a child health priority. Even the one national, targeted public health programme of vision screening at school entry has no data collection<sup>41</sup>, nor does the government have information on how much local expenditure it attracts. Obesity is the only part of the school entry health check for which data is collected.<sup>42</sup>

The quality of primary and secondary eye care data is generally known to be poor. Success in mitigating or preventing sight loss in children with learning disabilities is impossible to judge because no data is collected on access to eye care or outcomes. For example, it is not known how many children with learning disabilities are getting sight tests<sup>43</sup> because optical practices are not given a prompt to note if the child has a disability in the GOS returns made to NHS England, so no data is captured.

While there are figures on hospital paediatric ophthalmology activity<sup>44</sup>, the numbers of children with disabilities getting sight tests and eye care through secondary care are not readily available, if at all.

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<sup>41</sup> Hansard written answer 18 March 2015 <http://www.parliament.uk/business/publications/written-questions-answers-statements/written-question/Lords/2015-03-09/HL5567/>

<sup>42</sup> National Child Measurement Programme <https://www.noo.org.uk/NCMP>

<sup>43</sup> Health and Social Care Information Centre (2015). General Ophthalmic Services Activity Statistics. 2013-14.

<sup>44</sup> Health and Social Care Information Centre (2015). Hospital Episode Statistics. Admitted Patient Care, England 2013-14. See "Treatment Speciality".

# The impact on health and social care

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If the system isn't properly designed to meet the needs of children with disabilities, it could exacerbate the current financial pressures on health and social care.

If some children with disabilities receive no eye care they will be growing up in need of more costly health and social care interventions in adulthood if they develop avoidable sight loss.

If children with disabilities are staying with hospital eye clinics, which would rather not discharge them because of well-founded concerns about future access to community sight tests; or if they are referred into hospital because they fail vision screening and alternative community pathways are not available, then this also has an extra cost to the NHS.

According to NHS England, hospital attendances for ophthalmology account for the second highest number of outpatient attendances for any speciality.<sup>45</sup> The average reference cost for a paediatric ophthalmology appointment is £115.<sup>46</sup>

## No care: Brandon

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SeeAbility optometrist Lisa gave Brandon his first ever sight test when he was 16 years old. Brandon is on the autism spectrum, he is largely non-verbal and goes to The Village School, a special school in North London.

"I found that Brandon can see very little with his right eye. Sadly, that eye has not developed as it could have done had he had an eye test when he started school at the age of four or five," says Lisa.

If Brandon had received treatment involving prescribed glasses and patching before the age of seven, he might be able to see perfectly today.

Sadly, there's not much SeeAbility can do for Brandon's vision in his right eye. After sharing the findings of his eye test with his parents and teachers, it's now known that Brandon refers to walk with people on either side of him – especially when going up the stairs. SeeAbility will continue to monitor his sight in both eyes to help Brandon in his transition into adulthood.

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<sup>45</sup> NHS England (2014). Improving eye health and reducing sight loss – a call to action.

<sup>46</sup> Department of Health (2014). National schedule of reference costs: the main schedule (2013-2014). See Total Outpatient Attendances.



*No one knew Brandon could see very little out of his right eye.*

## **Hospital care: Tara**

Tara<sup>47</sup> is 16 and has cognitive impairment following a brain tumour in early childhood.

She is very longsighted with astigmatism. With her glasses, Tara can see well and is able to identify letters, which indicates a good level of vision. Without her glasses, Tara's level of vision is of a level that would make her eligible for registration as severely sight impaired.

Until SeeAbility came to her school, Tara was seen regularly at a hospital eye clinic to keep her glasses up to date because of concerns from them that if she was discharged she may struggle to access eye care in the community.

The University of Bangor has used data from SeeAbility's first year of service in special schools to calculate that a reasonably adjusted sight test costs circa £85.<sup>48</sup>

Its analysis concluded that a specialist sight test in a special school is cost comparable to other reasonably adjusted models of eye care for adults with learning disabilities. For example the community care pathway pays £81.31 for a reasonably adjusted sight test - a £60 enhancement on top of the £21.31 standard sight test payment from NHS England. The GOS contract itself operates a domiciliary payment of £58.87 for a first home visit if someone is unable to leave their home due to illness or disability (although it remains unclear if children with disabilities access home visits as there is no national data collection).

<sup>47</sup> Not her real name.

<sup>48</sup> Charles J et al. A cost-consequence analysis of conducting sight tests in special schools. Bangor University 2015. See [www.seeability.org](http://www.seeability.org).

# What have we learnt

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The studies described in this report have all had subtle differences of approach and design, but all were based on the premise that having a sight test in a special school provides a safe, familiar and convenient environment for the child and, with the support of appropriately trained professionals, gets results.

It was evident from all the studies that pathways for children with disabilities need to be as enabling as possible – which includes ensuring glasses prescribed are actually received, that children are supported to get used to them, and that communications to parents and teaching staff are straightforward.

Parental/carer support for the SeeAbility sight tests has been very high, with many comments on the reduced burden on family life from having appointments in school. Health professionals enjoyed the opportunity to work in partnership with pupils, teachers and families to produce positive outcomes for children.

In the SeeAbility service consent ranged from 40-80% of pupils in different schools, while the Bradford study operated an 'opt out' system, which gained 100% coverage. This shows that with the right encouragement it is possible to reach many more children through a targeted service in special schools.

# Recommendations

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The government and NHS England should work together to properly fund specialist sight tests and glasses dispensing in all special schools in England. Such a model is being developed and scaled up to capture the whole of the special school population in Wales.

SeeAbility believes it should be a matter of national policy for children in special schools:

- To be offered a comprehensive specialist sight test when they first start at school (which we recommend is a joint optometric and orthoptic assessment).
- To be offered an annual specialist sight test (or more often if necessary) performed in the familiar surroundings of their special school.
- To have their glasses fitted and be supported to get used to them, within their special school.
- To have their test results explained to them, their families and teachers, as well as their health professionals, throughout their school life and in transition to adulthood.

By focussing on a population of around 100,000 children in England<sup>49</sup> who will (by the nature of having to attend a special school) have some of the most complex needs or disabilities, the policy would offer the 'right care, at the right time and in the right place' to a group at high risk of sight loss, a group which is in real need of a reasonably adjusted model of care.

This arrangement would need investment – SeeAbility estimates it costs £85 to deliver a specialist sight test in a special school. The detail of how best to fund and deliver a model would need further discussion with policymakers and health planners. But an unreformed system risks much higher costs being borne by health and social care if sight loss is not prevented and there is unnecessary pressure on hospital eye clinics. It is a small price to pay for inequalities to be addressed, legal duties to be met, and for the government and the NHS to show they are serious about transforming care for people with learning disabilities and improving outcomes for children with special educational needs.

This would be a first major step forward but other reforms are needed. We are also calling for a national plan to improve eye care for all children with learning disabilities.

This should aim to:

- raise awareness of the high risks of sight problems they face amongst parents/carers, health professionals and those in the special educational needs sector;
- improve access to mainstream services and vision screening for children not at special schools;
- enable data collection on access to eye care and the outcomes children with learning disabilities experience; and
- ♦ ensure eye care and vision information is a key part of the child's special educational needs plan, and is shared appropriately between health and education.

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<sup>49</sup> Department of Education Special educational needs in England: January 2015 Table 5. Note there is this does not include data on independent special schools or post-16 special institutions.



children  
in focus  
campaign

# **An equal right to sight**

September 2015