Children in Focus Campaign
28 times more likely

Second year annual review
Executive summary

SeeAbility launched its Children in Focus Campaign in October 2013 with the aim of transforming eye care and vision for children with learning disabilities, and to ensure specialist sight tests are available in all special schools in England.

We have been working in conjunction with Cardiff University’s School of Optometry and Vision Science, to develop a programme of specialist sight tests\(^1\) to pupils in a cluster of London based special schools and to evaluate the findings from our service.

Visual impairment and blindness is relatively rare in the general population of children, however SeeAbility estimates that children with learning disabilities are 28 times more likely to have a serious sight problem.\(^2\)

This is our second annual report about our work and outlines the clinical findings from the sight tests that took place during the academic year 2014 - 2015.

A year of progress

On a practical level, it has been a year of great progress and development. We have expanded our work to cover six special schools in the London area. Working closely with headteachers, principals and staff, we have trained 118 learning and support assistants and teachers about the visual needs of children with learning disabilities and launched a range of downloadable resources on our website for health professionals, parents and teachers.

We have continued to bring together professionals from across the health and special educational needs sector to discuss developments in practice, including a conference for 100 delegates on Cerebral Visual Impairment (problems with vision processing in the brain).

Key findings from second year of sight testing

Our second year of data both reinforces our findings from our first year of testing, and adds new compelling evidence of need.

In the last academic year (September 2014 – July 2015) SeeAbility has provided eye care for 258 pupils, dispensed 87 pairs of glasses, and provided 261 sight tests.

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\(^1\) In this report we use the phrase ‘specialist sight test’ – which has no legal meaning – but is a term we use to describe a more in depth assessment of a child’s sight and eyes, not normally available in a community optical practice, which also involves the eye care professionals and specialist equipment/training needed for children with complex needs, and communication of the results to inform education and health planning for the child.

\(^2\) 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 (Emerson and Robertson, 2011. The estimated prevalence of visual impairment among people with learning disabilities in the UK).
We found:

- Over half of children we tested had a vision problem
- 43% of the new pupils we saw this year had no history of eye care
- 85% of those discharged from hospital eye clinics had no follow up community eye care
- 75% of the children with no history of eye care were noted as having autism
- 36% of the children we saw needed glasses

For the first time we have been also able to compare ophthalmic data from the special schools service with a mainstream school study. The need for glasses was significantly higher in the special schools we worked in – for example there was twice the prevalence of short-sightedness in younger children, while there was almost three times the prevalence of long-sightedness in older children. The need for strong prescriptions for glasses was also much greater in comparison.

But this is not just a case of demonstrating a high need for glasses in the special school population, as many other types of sight problems were identified. One in ten of the children had an eye health problem and 28% had a squint or related eye movement abnormality. There were a significant number of children who we suspected had Cerebral Visual Impairment.

These are similar findings from the first year of the campaign and from other studies in special schools. If these figures are replicated nationwide across special schools then thousands of children with learning disabilities continue to be missing out on eye care despite being 28 times more likely to have a serious sight problem.

Service evaluation

We believe our service model is delivering the following benefits:

**A special schools service targets the children that need eye care the most.** It meets a recognised health inequality and reaches children who are currently unable to access community eye care by providing that care in a safe, familiar and convenient place for the child. We found half of the children we tested had a vision problem, so the scale of need is evident.

**A special schools service can prevent permanent or unnecessary sight loss for a relatively low cost.** Children in a special school will have very high levels of refractive error and squints. These are very treatable conditions providing they are identified through the low cost intervention of a specialist sight test. Otherwise, if these issues are allowed to go untreated they can have a significant impact on a child’s education and development, their social skills and behaviour. At worst untreated refractive error and squints can leave a child with permanent sight loss – with long term costs to the NHS and social care.
A special schools service is an efficient model and reduces the need for hospital eye clinic visits for routine sight tests or glasses dispensing. 49% of the children we had eye care history for were under the care of hospital eye clinics, visits which bring associated challenges and time out of school. There is evidence that there are children being routed into or remaining with hospitals because there is no community alternative. For example, as many children cannot comply with a school entry vision screen the next step may be a hospital referral in some areas.

The model provides an alternative to this, so children can now be discharged to the SeeAbility service. Efficiencies are gained by operating in school because no appointment slots are wasted – if a child is ill or too anxious to attend their sight test, another child on the list can attend for their appointment instead.

A special schools service is child and family centred  The special school environment brings immense benefits in terms of a reducing a child’s anxiety in getting a sight test, complying with a sight test, and sustaining glasses wear. It also reduces the number of medical appointments children have to attend out of school and the logistical challenges this brings for family carers.

A special schools service can help address the needs of children with Autistic Spectrum Disorder (ASD). The difference in proportions of pupils with a history of eye care was statistically significant. Compared to their peers in special schools, pupils with ASD were much less likely to have been provided with eye care in the past. There were many cases of teenagers with autism for whom SeeAbility was giving them their first sight test.

A special schools service can provide a complete pathway of eye care. Many children in special schools simply need glasses, including specialist frames. Because the model includes a dispensing optician, SeeAbility is able to prescribe, fit and fix glasses – sometimes on the spot – as well as provide ongoing support with glasses wear. Without a service in school, children may have to wait for weeks without the glasses they need, or may not pick up their glasses at all, meaning they continue to miss out on their education.

The impact seen in school

One of the most reported impacts of the project was bringing knowledge of the child’s visual needs to parents, teachers and support staff. It can be the first time in years that anyone has explained to a parent or teacher in layman’s terms just why the child needs glasses, or even what their visual diagnosis means.

The other most reported impact was the change in behaviour seen in many of the children who we supplied with glasses. Teaching staff have fed back to SeeAbility that once a child could see better, they seemed happier, more engaged and less likely to exhibit frustration or challenging behaviour.
Next steps

Importantly we are in a situation now where NHS England accepts that its ophthalmic services contract must include special schools and we were delighted to be awarded the first ever NHS contract to work in special schools in England in 2015.

However that contract exposes how the legal, contractual and funding framework for NHS sight tests is not designed for children with complex needs. Currently the NHS pays a flat fee of £21.31 per sight test in a special school – the same as is paid for any ‘standard’ community sight test.

We made national and local headlines when we released a critique of the present system of eye care for children with learning disabilities in September 2015, in our ‘An equal right to sight’ report, and in turn this has led to the public, policymakers and professional bodies joining the call for a special schools sight testing programme. Over 3000 people signed a petition and 35 MPs have signed a parliamentary motion. In January 2016 we were delighted to host the Minister responsible for eye care in England, the Rt Hon Alistair Burt MP, on a visit to the project at Perseid Lower School, where he met pupils, parents and teachers.

Awareness is growing and there is a real sense of momentum to the campaign for change. In February 2016, the Welsh Assembly Government published its plans for a dedicated, nationwide special schools sight testing service in Wales. The onus is now on the Department of Health and NHS to follow suit in England.

SeeAbility would like to see NHS England develop a properly funded national programme, to deliver equality of access to the free annual NHS sight test to around 100,000 children in special schools who have some of the most complex needs and disabilities. Separate negotiations with over 200 local health commissioners for a special schools service in their areas will not deliver – the variability that currently exists in the delivery of eye care in special schools is testament to this.

This is a relatively small population of children, where a new national programme could help the NHS find the financial efficiencies it needs, and prevent unnecessary sight loss and poorer outcomes for children and young people with learning disabilities. Doing so would be a first major step forward in the reforms needed to deliver an equal right to sight for all children and adults with learning disabilities.
About SeeAbility

SeeAbility is a UK charity supporting people with sight loss and multiple disabilities. As well as providing specialist support (housing and care), we share our knowledge of supporting people with sight loss and learning disabilities proactively across the UK and act to improve and increase access to eye care and vision services for people with learning disabilities.

We have a wealth of information on our website including easy read factsheets about eye care and eye health; a functional vision assessment tool; videos; and details of optometrists who can support people with learning disabilities to have an eye test and access good eye care.

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This report can be printed and shared.

Please contact us for Braille, audio and other language variants.

Telephone: 01372 755 000   Website: [www.seeability.org/childreninfocus](http://www.seeability.org/childreninfocus)

Email: [childreninfocus@seeability.org](mailto:childreninfocus@seeability.org)

SeeAbility is the operating name of The Royal School for the Blind founded in 1799. Registered Charity No. 255913
Acknowledgements

The Children in Focus Campaign is led by SeeAbility and benefits from a collaborative approach with a wide range of organisations and individuals.

Particular thanks are given to our Children in Focus eye care team who deliver our specialist sight tests; the Children in Focus Campaign steering group who have brought their expertise and advice to the project; Dr Maggie Woodhouse, Principal Investigator for the Children in Focus Campaign, Cardiff University School of Optometry and Vision Science; Judy Bell, Consultant in special education (visual impairment and complex needs); and Professor Kathryn Saunders, Professor of Optometry and Vision Science, University of Ulster.

SeeAbility is also very grateful to Dr Nicola Logan, Senior Lecturer in Optometry and Principle Investigator for the Aston Eye Study, Aston University, for providing comparative data from her study of mainstream school children.

We would like to thank all the pupils, their parents and families, headteachers, principals and staff in the special schools we have been working with. Without their support this work would have not been possible.

Special schools that took part in the Children in Focus Campaign 2014-2015

- **Perseid Lower School** (ages 3-11 years) and **Perseid Upper School** (ages 11-19 years), London Borough of Merton.
- **Moorcroft School** (ages 11 – 19 years), London Borough of Hillingdon.
- **Grangewood School** (ages 3-11 years), London Borough of Hillingdon.
- **The Village School** (ages 3 – 19 years), London Borough of Brent.
- **Willow Dene School** (ages 3-11 years), London Borough of Greenwich.

We are grateful to all our donors and supporters for enabling us to continue our specialist work. We would like to pay special thanks to:

- Greater London Fund for the Blind
- John Lyon’s Charity
- The Hospital Saturday Fund
- Rutland Partners
- The Steel Charitable Trust
- Vision Charity
- Wates Foundation
- Worshipful Company of Spectacle Makers
Introduction

SeeAbility launched its Children in Focus Campaign in October 2013 with the aim of transforming eye care and vision for children with learning disabilities, and to ensure specialist sight tests are available in all special schools in England.

This is a report about our second year findings which includes analysed clinical data for the academic year September 2014 to July 2015. The first year report of the Campaign can be found at www.seeability.org/childreninfocus.

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 in the UK, by 2016, there will be over 23,000 children and young people with learning disabilities with serious sight problems, and over 193,000 children and young people with learning disabilities who will have some problem with their vision due to refractive error such as long and short- sightedness.

With visual impairment and blindness relatively rare in the general population of children, SeeAbility estimates that children with learning disabilities are 28 times more likely to have a serious sight problem.

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 preterm babies, who have a higher risk of visual problems and disability. There is also evidence that the more profound and complex the learning disability, the greater the likelihood that person will have visual impairment.

The sight problems children with learning disabilities experience might include:

- Refractive error – which is often high. Refractive error means the eye cannot clearly focus the images from the outside world due to short or long-sightedness, or astigmatism – related to the shape of the lens or the cornea of the eye.
- Amblyopia (reduced vision, sometimes called ‘lazy eye’).
- Strabismus (squint/eye turn).
- Cataracts (clouding of the lens in the eye).

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3 Emerson and Robertson, 2011. The estimated prevalence of visual impairment among people with learning disabilities in the UK.
4 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.
• Problems with eye movements such as nystagmus (involuntary eye movements) or poor eye movement control.
• Keratoconus (progressive changes to the shape of the eye’s outermost layer).
• Optic atrophy (damage to the optic nerve) or developmental abnormalities of the eye.
• Cerebral Visual Impairment (abnormalities with vision processing in the brain). This is often shortened to CVI and also sometimes called cortical visual impairment.
• Accommodative anomalies (problems with the eye’s ability to shift focus).

Many sight problems are both preventable and treatable, so early eye care is essential. Eye problems that remain undetected, such as squint, long and short-sightedness, may lead to lazy eye and, if untreated, can result in permanent damage, even the loss of vision in the worst cases.

If a child has a sight problem it is important that parents and school staff are aware of it, it is corrected or treated where possible, and/or teaching strategies can then be developed to incorporate the needs of the child. Different sight problems need different strategies and must always be tailored to the individual child. For example, where certain conditions limit a child’s sight, it will mean that even with the best possible pair of glasses their vision is still reduced.

Are children with learning disabilities accessing the eye care they need?

Every child or young person under 19 years of age, who is in qualifying full time education, has the right to a free NHS sight test. For those who are under 16 this is recommended annually, or more often if clinically required. It is a matter of policy to offer free NHS sight tests to children because sight is extremely important to a child’s learning, development and independence. The sight test and glasses vouchers are funded by NHS England at rates set by the Department of Health.

However children with learning disabilities are less likely to access timely, effective and appropriate healthcare including health promotion activities and less likely to take up preventative screening. This is as applicable to eye care as it is to other areas of health.

Evidence from studies in Scotland and Wales (Das, 2010; Woodhouse, 2012) have found that pupils in special schools are highly likely to have undiagnosed or untreated sight problems and are less likely to get access to the eye care they need.

SeeAbility’s Children in Focus Campaign is building a picture of the situation for children in special schools in England and findings confirm high levels of unmet need exists in England.

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9 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
The reasons why children with learning disabilities miss out is discussed in SeeAbility’s report ‘An equal right to sight’, published in September 2015.11

This report found that the clinical checks freely available in community optical practices or hospital eye clinics may not provide the reasonable adjustments a child with complex needs might require. It also found very little government data is gathered on eye care for children – let alone children with learning disabilities – so the Children in Focus Campaign is adding to the evidence base and information that other practitioners hold from their work in special schools.

There are many areas of England with no eye care in the special school setting, while some areas have commissioned more comprehensive input from eg. specialist orthoptists.

11 Please see the following link on our website for a full copy of the report [www.seeability.org/who-we-are/media-centre/research/an-equal-right-to-sight](http://www.seeability.org/who-we-are/media-centre/research/an-equal-right-to-sight)
2014 - 2015 was an important and busy year for the Children in Focus Campaign, with the sight problems experienced by children with learning disabilities gaining national attention and our work developing in a number of ways.

We expanded our service to other schools and began sight testing in Willow Dene School, in Greenwich in March 2015 and Grangewood School, in Hillingdon in May 2015, hence reaching six special schools.

In this academic year (September 2014 – July 2015) SeeAbility has provided eye care for 258 pupils, dispensed 87 pairs of glasses, and provided 261 sight tests.

In March 2015 we published our first year report on sight testing undertaken in four London special schools in the 2013 - 2014 academic year. Our findings showed that:

- 37% of children had no history of eye care
- Three quarters had no follow up eye care in the community once discharged from the care of hospital eye clinics
- A third needed glasses

In 2015 we also began our training programme for teaching staff in special schools. Designed to help staff understand and be alert to the visual needs of children with learning disabilities our training covered subjects such as explaining when glasses need to be worn and the impact on learning of being without necessary glasses; how to identify if a child may be struggling with their vision and how we test vision.

This work has also allowed us to train teaching staff in strategies to support adaptation to glasses and changing prescriptions, working towards improved success rates with glasses wear for the children. We have trained 118 learning and support assistants and teachers so far.

In Spring 2015 important work began with Ulster University’s Vision Science Research Group which developed a new report we are using to explain the results of an eye examination. So much of what we have heard from parents and teachers during the project has been the need for ‘plain English, non-medical terminology’ that helps people understand just what a child can see and what tests have been performed. These reports also help support parents and teachers with strategies, such as children’s adaptation to glasses, or how to support visual needs at school and home.
We continued to bring together professionals from across the health and special education needs sector to discuss development in practice and identify just what we could do to support their information and training needs. In June 2015 we ran our second conference on Cerebral Visual Impairment (CVI) with presentations from specialists from Great Ormond Street Hospital, and parents of children with CVI. Over 100 delegates, mainly Qualified Teachers of Visual Impairment (QTVIs) whose role is to educate children and young people with visual impairment gained up to date information on CVI and strategies for identifying and engaging children with the condition.

In Summer 2015 we launched a range of downloadable resources on our website www.seeability.org/childreninfocus about the vision needs of children with learning disabilities. These resources, for parents, carers, teachers and eye care professionals have been written with the support of clinicians and those experienced in teaching visually impaired children. The resources provide information and advice on common eye conditions, what an eye test involves and examples of how to record a child’s vision needs in their Education, Health and Care Plans (EHCPs).

In August 2015 SeeAbility was granted a General Ophthalmic Services (GOS) contract by NHS England. The NHS had long recognised that day centres and residential care settings were places where NHS sight tests could take place, but it had yet to accept that NHS funded sight tests could take place in special schools.

SeeAbility made a case that the NHS could and should take a first step in reasonably adjusting its approach to children with learning disabilities, and we were pleased to be the first NHS GOS contractor to be able to operate in special schools.

However, the legal, contract and funding framework for NHS sight tests is not designed for children with complex needs. Currently the NHS pays a flat fee of £21.31 per sight test in a special school – the same as is paid for any ‘standard’ community sight test (a fee that is widely acknowledged not to meet even these usual operating costs). Analysis from the University of Bangor\(^\text{12}\) estimated that our first year of work cost £85 per sight test undertaken within a special school.

We also met with NHS England officials, and took them on a visit to see our project in action to discuss how we might shape our case for a programme that reaches out to all special schools in England.

Meanwhile the Clinical Council for Eye Health Commissioning – the single, national clinical voice in England providing expertise on eye health services, social care and ophthalmic public health to commissioners, providers, clinicians and policymakers – endorsed the report’s recommendations for a comprehensive and targeted programme of eye care for children in special schools in England following a presentation by SeeAbility.

In September 2015 we used our findings to outline a case for reform of NHS funded eye care for children with learning disabilities, published in our ‘An equal right to sight’ report. Our work in The Village School, Brent was a major feature on ITV’s London Tonight and the fact that many children with learning disabilities were missing out on eye care hit the news across radio and print.

Our report was accompanied by support from professional bodies such as the College of Optometrists, Faculty of Public Health and the National Association of Special Educational Needs, quickly gaining the interest and attention of policymakers and raising political interest in this work.

In the autumn, Siobhain McDonagh, MP for Mitcham and Morden visited the project in Perseid Lower School, Morden, and was inspired to lead a Westminster Hall debate in parliament and secure an ‘Early Day Motion’ or EDM, enabling other MPs to put their names behind a parliamentary call for action. So far 35 MPs have signed the EDM. Matthew Pennycook MP and Clive Efford MP also visited the project in Willow Dene School, Greenwich, which teaches pupils from both their constituencies.

By the end of the year over 3000 people had signed a petition calling for reform. Comments flooded in from parents and teachers of children with learning disabilities, some of whom shared their experiences of trying to access eye care for their child in the community.
3153 people signed our petition. Here are some of their comments:

“A wise and special cause that should have full support of our government and could help so many children in the future”

“My son refuses to co-operate with sight tests and had to have one under a general anaesthetic. Perhaps if he had tests at school in a familiar environment he might be more likely to co-operate and avoid the risks of a general anaesthetic”

“Good luck with your very worthy campaign. Let’s hope the government will sit up and take notice”

“As headteacher of a special school I fully support this initiative”

“My daughter was accident prone and every professional told me it was because of her disability. Years later discovered she couldn’t see out of one of her eyes”

“Every child deserves a sight test to ensure they can fully embrace the life they live”

“Working in a special school I recognise the huge benefits that could be gained from this scheme”

“Children with autism are visual learners and maintaining healthy vision is vital to their education”

“Accessing an optician would be exceedingly difficult for my son with severe sensory processing difficulties. A visit to his school would be a far more comfortable experience”

“Good luck in your campaign. I think it is a vital service that should be available to every special needs school”

“My child has learning disabilities and cannot communicate how well she sees. Wearing her glasses makes a huge difference to how she functions”

“My son’s special school is a place he feels at ease, unlike a clinic or a hospital which has to involve meticulous preparation in getting him there and even then the waiting time causes him huge stress and anxiety”
The Minister for Community and Social Care, the Rt Hon Alistair Burt MP had responded positively during the Westminster Hall debate on what the government and NHS England might do to reform the present system. We were delighted when he then visited Perseid Lower School to see the sight testing project in action. Mr Burt, below pictured centre, met pupils Naana (left, with her mum Amanda) and Ellie (right, with her mum Alyson), and was handed our petition. He later tweeted he was “deeply impressed” by the project.

![Image of Mr Alistair Burt with pupils Naana and Ellie]

Crucially we know the next step for policymakers is to have a convincing clinical and business case that a special schools model can work on a nationwide level.

SeeAbility has set up a task and finish group with representation from the Royal College of Ophthalmologists, the British and Irish Orthoptic Society, the College of Optometrists, the Association of British Dispensing Opticians, and the Local Optical Committee Support Unit (LOCSU) to develop a Framework Document for a special schools programme in England. We are very grateful to all the professional bodies and their representatives for their support for this work. The group will report to NHS England in Spring 2016.

Representatives of the Children’s Vision Service Advisory Group in Wales are also advising this group, as separately the Welsh Assembly Government is currently consulting on a programme for special schools in Wales. The fact that Wales is now on the road to a special schools service provides a very positive note to conclude on.

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How does the SeeAbility service work?

SeeAbility uses a multidisciplinary service model involving suitably experienced optometrists, orthoptists and a dispensing optician. We recruited a dispensing optician in early 2015 as we recognised their input would bring the additional expertise needed, and release more of optometrist time (as they were previously also fitting and dispensing glasses) for the specialist sight testing. The day to day operation of the service is managed by our Optometry Practice Manager.

More on the logistics, the tests undertaken, and the equipment used in the project can be found in our first annual report www.seeability.org/childreninfocus.

The term ‘specialist sight test’ has no legal meaning – we use as appropriate throughout the report as shorthand for describing the model that SeeAbility has used. At present there is no nationally recognised specialist qualification for clinical practice in special schools, but this is something we would like to see developed alongside the framework and testing protocols we are developing.

We ensure that children have sufficient time for their test. We aim to see 6 children a day – which averages at 40 minutes for their sight to be examined, but can vary depending on how much a child might be able to tolerate or engage with the testing. In all cases the children were given as long as they needed to get their sight examined and where necessary this might mean breaking up the examination so a child was seen on more than one occasion.

If children were less inclined to come and see the team in the testing room, the specialist sight test went to them, in their own classrooms or even the playground, if appropriate.
The key elements of the service, all of which is delivered free of charge, are:

- Prior to commencing a service in an area, SeeAbility contacted the local paediatric ophthalmology and orthoptic departments and the school's paediatrician, nurses and Qualified Teachers of Visual Impairment (QTVI) to map existing ophthalmic services and establish good lines of communication, including onward referrals where necessary. Not every area has the same structures or referral mechanisms so we tailor the model to local circumstance.

- Parents/carers who opt for their child to be given a specialist sight test in school, are given more information, the option to attend on the day of testing, and are asked to fill in eye health history for their child, using SeeAbility's ‘About your child and their eyes’ form. This form can be viewed at [www.seeability.org.childreninfocus](http://www.seeability.org.childreninfocus).

- Children starting school at 4 to 5 years old are given a joint optometric and orthoptic assessment. Ensuring orthoptic involvement is a key recommendation of UK national screening committee guidelines for childhood vision screening – in practice this usually takes place at school entry. Orthoptists investigate, diagnose and treat defects of binocular vision and abnormalities of eye movement. Children that needed further investigation were referred onwards to the hospital eye clinic.

- Optometric led specialist sight tests were offered to all children in the schools that took part in the service and were provided for all children of all ages for whom we had consent. Further orthoptic input could be arranged at the school as well as onward referral if needed. Pupils had follow up appointments according to individual needs.

- A school based spectacle dispensing service supported by a dispensing optician was provided. Parents were asked if they wanted the team to fit glasses or were given the option of taking a copy of the prescription (and corresponding voucher amount) elsewhere for dispensing. The SeeAbility team worked with children to help them get used to their glasses and provided specialist frames, bespoke adaptations, adjustments, repairs and replacement glasses as needed.

- Results of the specialist sight tests were communicated to parents, teaching staff and Qualified Teachers of pupils with Visual Impairment (QTVIs) using SeeAbility’s ‘The results of your child’s eye test’ which can be found at [www.seeability.org/childreninfocus](http://www.seeability.org/childreninfocus). The form explains the findings of the examination in a clear way and gives an action plan. Potential visual problems, including CVI and the need for spectacles could be shared with the QTVI and findings co-ordinated where possible within the Education, Health and Care Plan for the child.

- Children moving on from the school were also provided with a leaver report summarising what had happened to date with their eye care and advising on local
optical practices which may be able to support their need for regular sight tests in adult life.

SeeAbility also evaluates the service with the support of the schools we are working in, to constantly refine the model and gain feedback from parents and schools on what can be improved. SeeAbility is tremendously grateful to the schools we have been working with.
Second year findings

Cardiff University School of Optometry and Vision Science have provided an analysis of the clinical data and a summary of the findings are below. Statistical analysis was also used to compare some of the findings.

Expanding on the findings of our first year’s work, this year the service reports on:

- The extent of visual problems in this cohort of children (not just refractive error).
- Comparison with a mainstream school children study of refractive error.
- Unmet need amongst children noted as having Autistic Spectrum Disorder (ASD).

SeeAbility is very grateful to Dr Nicola Logan, Senior Lecturer in Optometry and Principle Investigator for the Aston Eye Study for providing comparative data from her study of mainstream school children. The Aston Eye Study is an ongoing cross-sectional study to determine the prevalence of refractive error and its associated ocular biometry (measurement of eye dimensions). The study uses a large, multi-racial sample of mainstream school children from the metropolitan area of Birmingham (UK). For more information on the Aston Eye Study please see: www.aston.ac.uk/lhs/research/health/org/eye-study.

Ethics

In this academic year as the project did not involve NHS patients, their relatives, staff or premises it did not need NHS ethics approval. Scrutiny by the School of Optometry and Vision Sciences Research/Audit Ethics Committee at Cardiff University was sought and the project was approved. The project was considered by the Committee to be a service evaluation.

Numbers of pupils who had a sight test in 2014 - 2015 academic year

In the 2014 - 2015 academic year we saw 258 children across six schools. 180 children were new to the project, and 78 were previously seen in the first year of the project.

Two of the schools, Grangewood and Willow Dene were involved in the SeeAbility scheme for the first time, thus there were no previous service users.

For the schools where we had been working since October 2013 we still have to gain annual consent for each child - uptake of sight tests is on average 39% which is still higher than the annual uptake of NHS sight tests amongst children of all abilities – which currently stands at 21%.

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Ages and diagnosis of pupils who had a sight test

The age groups of the pupils are shown in the figure below. For ease of presentation the pupils were divided into the age groups below.

A third of children we saw had Autistic Spectrum Disorder (ASD), a quarter had global developmental delay and one in ten had Cerebral Palsy. Many of the children also had other lower incidence conditions.

It should be noted that this information was based on the forms we collected from the children prior to the specialist sight test which asks for primary special educational need. It is highly likely many of these children will have a mixture of other needs or other diagnoses that would be recorded by their GP or in their Education, Health and Care Plan.
Previous history of eye care amongst new children

Excluding children already seen by SeeAbility, across all six schools there were 180 new children to the project. We asked for previous history of eye care on the forms we gathered from the new children.

Excluding those children we had no information on, 43% of these new children to the service had no previous eye care history.

85% of those under care of hospital eye clinics but then discharged had no follow up eye care in the community.

11% of children with no eye care history were 12 years or older – the oldest pupil with no eye care history was 19 years of age.

It also was clear that the majority of eye care experienced by children in the special schools we worked in was from hospital eye clinics. 49% of the children we had eye care history for were under the care of a hospital eye clinic. Very few children reported eye care at a community optician.

For children now being seen by SeeAbility regularly (i.e. seen the previous year), 48% had been discharged by the hospital eye clinic and 33% currently remained under the hospital eye clinic as they are in need of continued clinical treatment and observation.

The age ranges of children receiving eye care under the hospital eye clinic were as follows:

- 42% were 4 - 7.9 years
- 30% ages 8 -11.9 years
- 28% ages 12 years and older.

Children with Autistic Spectrum Disorder (ASD)

A new area covered by this year’s report is an analysis of whether pupils with ASD were in some respects less likely to be engaging with eye care in the community. As previously noted, diagnosis or reported need was based on school or parental reports on the form received by SeeAbility prior to the specialist sight test, so the data should be taken with some caution. Excluding those children for whom no general diagnosis was recorded, and where there was no information recorded on previous eye care history, we could assess records for 127 children.

Three quarters, i.e. 75%, of children with no history of eye care had ASD and they were also less likely to be under the care of a hospital eye clinic. The difference in proportions of pupils having eye care was statistically significant, i.e. compared to their peers in special schools, pupils with ASD were much less likely to have been provided with eye care in the past.
Glasses prescribed

33% of new pupils seen – 55 pupils - needed glasses or a change in glasses (18% needed glasses for the first time or a change of prescription, the remainder no change in their current spectacles just replacement for fair wear and tear).

Altogether, 36% of all pupils seen (92 pupils) required glasses.

Of the 63 children with no history of eye care 14% (9 pupils) - required glasses.

SeeAbility provided all the glasses for free to the children and adapted them for their needs (e.g. flexible frames). This year only one parent said they would prefer to choose their glasses at a high street optician rather than have them dispensed at school by SeeAbility. Specialist frames, straps and frame adaptations were provided as needed.

QTVI input

Out of the total of 258 pupils, 42% (109 pupils) were referred to the QTVI, demonstrating the high level of need for visual support and input amongst this cohort of children.

Clinical findings

Over half (50.2%) of children we gathered data for had a vision problem.

The following vision problems were identified.

i) Refractive errors (the eye’s ability to focus)

For the first time, an analysis was performed on the level of refractive errors found amongst the children in the SeeAbility project. In the special schools setting our optometrist will refract using a retinoscope, which is a tool that can assess refractive error, even from a distance, if a child is uncomfortable with someone getting too close to them.

27.3% of pupils were short-sighted (myopic), 13.9% were long-sighted (hyperopic) and 31.3% had astigmatism. 3% of children seen were prescribed glasses for accommodative insufficiency.

How does this compare with mainstream schoolchildren?

To assist comparison with the general population of children, SeeAbility is very grateful to Dr Nicola Logan, of Aston University, who has been researching the level of refractive error in mainstream school children (for more information see page 20).

The Aston study recorded refractive error among 647 mainstream school pupils in Birmingham, which has a wide ethnic variation, as do the London boroughs of the schools
taking part in the SeeAbility service. The Aston study used two age groups, 6 - 7 years and 12 - 13 years. To aid comparison we have segmented our data into three age groups.

Statistical analysis shows that there is a significant difference amongst both the younger and older age groups in terms of long-sightedness and short-sightedness, and amongst the older age group in terms of astigmatism.

For example, when compared to their mainstream peers, in the special schools there was:

- Twice the prevalence of short-sightedness amongst younger children
- Almost three times the prevalence of long-sightedness amongst older children
- Almost twice the prevalence of astigmatism amongst older children

The distributions of refractive errors are shown in the bar chart below.

If a typically developing young child is long-sighted the eyes will usually gradually correct (a process called ‘emmetropisation’) as seen from the declining numbers of children who are long-sighted in the Aston study. However, it is interesting this is apparently not happening in the special schools pupils we tested.

In ophthalmic care, the degree of focussing (refractive error) is measured and recorded in units called dioptries illustrated by the letter ‘D’. The higher the number measured in dioptries, the higher the refractive error and therefore the greater the blur experienced if refractive error is not corrected. It can be seen that children in the special schools were more likely to be experiencing moderate to high refractive errors than their mainstream peers, with a statistically significant difference across both age groups. High short-sightedness (-6.00D or more) was ten times as prevalent in the younger age group.
For the SeeAbility project refractive errors ranged from -30.00D to +6.50D. -30.00D would mean a child could only see 3cm in front of them and beyond this the world would be blurred.

For some children who had no history of eye care refractive errors ranged from -6.00D to +4.00D. In the case of uncorrected -6.00D short-sightedness, the child could only see clearly up to 18cm in front of them. In the case of +4.00D of long-sightedness close up vision is likely to be significantly blurred as well as some blurring of distance vision, becoming worse when the child is tired. This level of long-sightedness is likely to make vision unstable and is often associated with a squint – and, as was the case here – the squint was corrected with glasses.

**ii) Squint and orthoptic anomalies**

This year SeeAbility saw many more children of ages 4 to 5 years old, as new starters to their school, so there was greater orthoptic involvement to assess a child for any orthoptic anomalies i.e. issues related to the eyes ability to work together. Most commonly, this can present as a squint. 48 pupils (19%) were examined jointly by the optometrist and orthoptist.

Overall, 71 pupils (28%) had strabismus (a squint) or an orthoptic anomaly i.e. issues related to the eyes ability to work together. Studies have put the estimated prevalence of childhood squint in the general population at 2.1%, again demonstrating the high prevalence of sight problems in special schools.\(^\text{15}\)

Squints are usually picked up where a child has an obvious eye turn and are often treatable with glasses and patching, but without treatment a child can be suffering blurred vision.

vision, double vision and a lack of depth perception. To avoid double vision, the brain usually starts to ignore the pictures coming from the eye with the squint, leading to that eye developing reduced vision (amblyopia or ‘lazy eye’), potentially permanently.

Orthoptist Rhiannon has recently begun to work in joint clinics with SeeAbility’s optometrists:

“The Children in Focus model has enormous benefits over the traditional, NHS eye clinic testing. A true multi-disciplinary team approach in an environment familiar to each child. For an orthoptist, working this way improves engagement; having an optometrist present aids diagnosis and management. Most importantly, working within this model keeps the distress levels of the children to a minimum.”

iii) Ocular disorders

Other than refractive error and squint, twenty-eight pupils (11%) were recorded as having another eye abnormality or eye health issue, ranging from nystagmus (abnormal eye movements) and cataracts (clouding of the lens of the eye) to eye conditions such as blepharitis or conjunctivitis that can cause irritation and soreness to the eyes. Conditions such as blepharitis and conjunctivitis were managed by the optometrist, where necessary in collaboration with the child’s GP.

Six pupils (21%) were referred on for treatment following the eye examination, one pupil to the GP (hayfever) and five pupils to hospital eye clinics (keratoconus, cataracts, ptosis and nystagmus). Good links were developed with local ophthalmologists, so that wherever possible children were only referred if there was a change in their visual status or a previously undiagnosed ocular condition requiring an ophthalmological opinion or management was identified.

iv) Cerebral Visual Impairment (CVI)

Even if a child’s eyes are healthy and focussed, there can be problems processing visual information in the brain – known as Cerebral Visual Impairment or CVI. Diagnosis will rely more on observable behaviours. We suspected CVI as an attributing factor in 29 pupils (11%) who we referred on to an ophthalmologist and/or QTVI for further investigation where appropriate. Two pupils were referred to an ophthalmologist for previously undiagnosed suspected CVI.

v) Visual acuity

Visual acuity is a measurement of the smallest degree of detail an eye or two eyes together can define. This is normally scored as the smallest line of letters that can be seen on a chart (measured and reported according to the ‘LogMAR’ scale). This is often tested
differently for children with learning disabilities using card systems showing pictures, objects or gratings.¹⁶

It is assessed as the child ‘presents’ at the sight test, in other words if they come with or without their glasses on. It is usually reported on the basis of what detail a child can see in their best eye so the optometrist will also try to cover a child’s eye to test which is the better eye.

Using the World Health Organisation criterion for low vision (LogMAR 0.5 or poorer in the better eye), 41 pupils (27.5%) had low vision on presentation. Compared with the Aston study in mainstream schoolchildren, 17 of the 647 pupils (2.6%) presented with low vision. Of pupils with low vision for whom previous eye care history was available, 28% (9 pupils) had no previous eye care history.

It can be challenging to reliably record visual acuity in children with learning disabilities, which is reflected in these findings:

- Presenting acuity could only be recorded in 149 cases (58% of children tested)
- Only around a third of pupils (35%) could comply with having their eye covered to test the vision in each eye (monocular vision). This is often used as a way of screening to check for amblyopia or ‘lazy eye’ or the need for refractive correction in just one eye.
- For those children where no acuity was recorded, 81% of cases related to lack of co-operation.

Statistical analysis indicates that pupils with ASD were significantly less likely to be able to provide a reliable acuity score.

In the UK school entry vision screening programme, if a child cannot see a certain level of detail with each eye separately, according to the LogMAR scale, they will be referred on for further, fuller tests dependent on local criteria or level of acuity. For example, parents may be advised to take their child to a community optician or referred into secondary care.

Only 37 pupils (14.3%) of those we saw would ‘pass’ current vision screening criteria. Assuming the 101 pupils unable to co-operate for acuity testing would automatically be referred for further testing, a vision screen in these special schools would result in a referral rate of 85.7%. In the Aston study of mainstream schoolchildren, only 119 pupils (18.4%) would fail a vision screening test.

¹⁶ The tests used here were Keeler cards, Cardiff Acuity Test and Kay’s singles, all considered non-crowded, and the Kay’s crowded test.
Discussion

Our second year of data both reinforces our findings from our first year of testing, and adds new compelling evidence of need. Compounded by findings from other exemplar services and studies in special schools across the UK, we believe the case for a national special school programme can be comprehensively made.

We are very grateful to the following clinicians for information they have provided on their work:

- Veronica Greenwood, Head Orthoptist, Warrington and Halton Hospitals NHS Foundation Trust. Veronica has provided audited data and observations from her service covering 6 special schools and child development centres. Audited data is from 378 children seen and from parental satisfaction surveys.
- Miss Rachel Pilling, Consultant Ophthalmologist, Bradford University Hospital Teaching Trust. Rachel has provided a personal communication on the experience of providing visual assessment to 199 pupils in special schools in Bradford.
- Dr Louise Gow, optometrist at Action for Blind People, on her qualitative investigation of primary eyecare of children with ASD.
- Professor Kathryn Saunders, Vision Science Research Group, University of Ulster, on the Group’s study of visual function of children with ASD in both special and mainstream education.

Our service evaluation shows:

**A special schools service targets the children that need eye care the most.** It meets a recognised health inequality and reaches children who are currently unable to access community eye care settings by providing eye care in a safe, familiar and convenient place for the child. We found half of the children we tested had a vision problem so the scale of need is evident.

Yet despite this high level of need, over 4 in 10 (43%) of new children we tested this year had no previous eye care history. Very few children reported receiving eye care at a community optician although this is where most children are expected to exercise their right to a free NHS sight test.

This is very similar to our findings from the first year of the Campaign. If this is replicated nationwide across special schools then thousands of children with learning disabilities continue to be missing out on eye care despite being 28 times more likely to have a serious sight problem.

It is also clear that even children with known sight problems are not accessing community alternatives once discharged from the specialist setting. 85% of those discharged from hospital eye care services had no follow up eye care in the community.
Ella

Ella has quadriplegic Cerebral Palsy, no speech and communicates using her eyes and with eye gaze. She was seen regularly in the hospital until around the age of 12 when she was discharged. She didn't have another eye test until she was 18 when the SeeAbility optometrist discovered that Ella had become short-sighted (-2.50D). This means everything beyond 40cm was blurred for Ella. Developing short-sightedness is fairly common for teenagers, but in Ella’s case she was not able to tell anyone about it.

She now loves her new glasses. Because Ella uses a wheelchair with a headrest it was necessary to fit her with specially adapted frames so that her glasses don’t get pushed out of place by head movements.

On World Sight Day 2015 the school held a craft competition to make glasses and Ella won first prize!

A special schools service can prevent permanent or unnecessary sight loss for a relatively low cost. Children in a special school will have very high levels of refractive error and squints. These are very treatable conditions providing they are identified through the low cost intervention of a specialist sight test. Otherwise, if these issues are allowed to go untreated they can have a significant impact on a child’s education and development, their social skills and behaviour. At worst untreated refractive error and squints can leave a child with permanent sight loss – with long term costs to the NHS and social care.

This year 36% of all pupils seen required glasses. This is in line with other UK studies that have shown up to half of pupils in a special school may need glasses. There was a significant difference in refractive error and strength of glasses prescription experienced by children in the special schools compared to their mainstream school peers. Significantly the level of squint is also very high in special schools (28%). The high levels
of refractive error and squint is also confirmed in the Warrington special schools service audit.

**Jacob**

Jacob (not his real name) has autism and had his first sight test at school aged 5. We found he had a squint and significant long-sightedness in both eyes (+4.00D). Without his glasses, Jacob’s vision will fluctuate as he struggles to focus to overcome his long-sightedness and his close vision will likely be particularly blurred.

If left uncorrected, the squint would have led to amblyopia (lazy eye). Jacob now loves his glasses and cries if they are taken away. Jacob is a very active little boy and his glasses can get broken. Being a regular presence in school means that when this happens we can repair the glasses quickly and conveniently without the need for making an appointment out of school and a wait to repair.

![How Jacob saw school dinner before](image1)

![How Jacob sees school dinner with his glasses](image2)

By recognising poor sight for the first time in a number of children with no previous history of eye care, the service helps ensure children are on the right pathway of care – whether this is referring on 8 pupils for input of a QTVI to provide support and strategies, accessing orthoptic advice and treatment, helping children access refractive correction with glasses, or children with ocular abnormalities being referred on for medical treatment.

**A special schools service is an efficient model and reduces the need for hospital eye clinic visits for routine sight tests or glasses dispensing.** 49% of the children we had eye care history for were under the care of hospital eye clinics, visits which can bring associated challenges and time out of school. There is evidence that there are children being routed into or remaining with hospitals because there is no community alternative. For example, as many children cannot comply with a school entry vision screen the next step may be a hospital referral in some areas.

The model provides an alternative to this, so children can now be discharged to the SeeAbility service. Efficiencies are gained by operating in school because no appointment
slots are wasted – if a child is ill or too anxious to attend their sight test, another child on the list can attend for their appointment instead.

With the children now being seen by SeeAbility as regular patients (i.e. seen the previous year) we worked with ophthalmologists to discuss those children they could comfortably discharge to our service. Alternatively if the ophthalmologist felt they would like to keep some of the younger children with profound and multiple learning disabilities under annual review for now, SeeAbility was able to provide an in-school spectacle dispensing service.

Some parents reported their children had been refusing to attend hospital eye clinic appointments through association with stressful situations - sometimes due to the waits involved, sometimes because the children were aware there would be eye drops. The issue of ‘do not attends’ concerns all hospital trusts along with waits for services.

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**Tara**

Tara (not her real name) is a teenager with cognitive impairment following a brain tumour in early childhood. She is very long-sighted with astigmatism. With her glasses, Tara can see well and is able to identify letters of a size 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. She gets so upset going to hospital eye clinics that mum has to arrange for her siblings to come so Tara thinks it’s a family outing and will experience less anxiety.

The tariff (payment) for a first paediatric ophthalmology appointment is £149\(^{17}\) and there is evidence from practitioners that a child may require more than one hospital visit to complete a full assessment of their visual status. In Warrington’s special school service, which has modelled projected savings for two of the schools it works with, based on hospital tariffs and evidence that a child may require multiple hospital visits to get the same result, the service is estimated as providing over £12,000 saving per annum to commissioners.

**A special schools service is child and family centred**  The special school environment brings immense benefits in terms of reducing a child’s anxiety in getting a sight test, complying with a sight test, and sustaining glasses wear. It also reduces the number of medical appointments these children have to attend out of school and the logistical challenges this brings for parents/carers.

Feedback from parents on the SeeAbility service has been very welcoming. The calm, familiar setting in school, with trusted staff and peers around them, relieves stress and

anxiety for the child. The other benefit of operating in special schools – often spoken about by parents – was unlike hospital clinic appointments, there was no travel involved and greater flexibility to re-schedule/ carry out different elements of the tests on different days/at different times without any need to take the child out of school or book time off work. Similar feedback has been given in other services – notably Warrington’s special school service which has high parental support and satisfaction.

Mum Alyson and daughter Ellie

Alyson: “Ellie finds hospital visits stressful and gets anxious if her routine is disturbed. Having a sight test at school means the teacher can communicate with the optometrist and she doesn't have to miss an entire day of her classes.”

What the project shows is that almost all children can have a specialist sight test if they feel prepared and a personalised approach is taken – this year all but two children of 258 could be refracted to see if they needed glasses and the reasons for this were related to their ocular conditions, not behaviour.

Parent at Moorcroft School

“The whole experience provided by SeeAbility was excellent. The team were very good and seemed familiar working with pupils with SEN. This is really important to me. Also the tools that the testing team used were really good. My daughter was completely at ease during the sight test because of the positive energy the testing team had. I even told the optician how surprised I was they managed to shine a light in my daughter’s eyes and get so close to her”.
Absolutely key was the understanding that teaching and support staff could bring to the testing situation on the day – they knew the strategies that would help a child engage or could be alert to any potential distress or triggers for challenging behaviour. The presence of teaching staff also allowed for immediacy of feedback so visual findings and strategies could be discussed almost straight away.

A special schools service can help address the needs of children with ASD. The difference in proportions of pupils without a history of eye care was statistically significant. Compared to their peers in special schools, pupils with ASD were much less likely to have been provided with eye care in the past. There were many cases of teenagers with ASD for whom SeeAbility was giving them their first sight test.

**Nadia**

Nadia (not her real name) has a diagnosis of ASD. Despite being in her teenage years she had no history of eye care or glasses. On questioning, Nadia’s learning support assistant and teacher had noticed that she often ‘screwed up her eyes’ to look at things but attributed this to her ASD (unusual eye behaviours are commonly associated with ASD). Nadia’s parents had written that they did not think she needed glasses, but SeeAbility could test her eyesight.

Using retinoscopy (measuring eye focusing by shining a light into the eyes whilst holding up lenses in front of the eyes), the SeeAbility optometrist found that Nadia did need glasses. Her prescription in each eye was +4.50D of long-sightedness with -3.00D astigmatism. The SeeAbility dispensing optician fitted Nadia with her new glasses.

Nadia loves her glasses and always wears them. Jacky, the school’s healthcare advisor, said that she won’t forget Nadia’s face when they were first put on, as Nadia looked around the room and became totally engaged with her surroundings.

There could be many reasons for this unmet need. For example, it may be that children with ASD are less likely to be under the care of a paediatrician or hospital services where visual issues may be picked up. There is also a risk of diagnostic overshadowing with this group of children, with sight problems – as with Nadia’s above - mistakenly attributed to
autistic behaviours. Parents may not believe it is possible for their child to tolerate a sight test, or sustain glasses wear. A community optical practice or a long wait at a hospital eye clinic may be daunting for some children with ASD.

Coupled with the fact that children with ASD do have an increased likelihood of sight problems, special attention needs to be paid to children with ASD. For example, a recent study\(^{18}\) has shown that 15% of children with ASD have an accommodative deficit, and further studies to follow (personal communication, Professor Kathryn Saunders) will indicate squint is more common amongst children with ASD. Astigmatic errors are also significantly greater in magnitude and prevalence.\(^{19}\)

Work undertaken by Dr Louise Gow, at Action for Blind People\(^{20}\) has stressed the importance of improved optical professional awareness of ASD, and helping a child with ASD feel in control of their sight test with personalised adaptations and strategies.

**A special schools service provides a complete pathway of eye care** for many children in special schools who simply need glasses, including specialist frames. Because the model includes a dispensing optician, SeeAbility was able to prescribe, fit and fix glasses – sometimes on the spot – as well as access ongoing support. Without a service in school, children may have to wait for weeks without the glasses they need, or may not pick up their glasses at all meaning they continue to miss out on their education.

As refractive errors and strength of prescription tends to be higher for this group of children, the impact of not having spectacles on a child’s education and quality of life will be more significant than for children without SEN. There is strong evidence that refractive correction has a real impact on children with learning disabilities (Williams\(^{21}\)).

It was also clear from SeeAbility’s service that a number of children needed specialist or specially adapted frames. Some came into the service wearing frames that were not fitting them properly.

Children in a special school often require significant support with adapting to new glasses and it is well known that glasses are often prescribed for but not worn by (or even dispensed to) children with learning disabilities. This may be due to a number of issues, for example, a lack of understanding around the importance of wearing glasses amongst parents, carers and teachers.\(^{22}\)

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\(^{20}\) A qualitative investigation of primary eyecare of children with ASD, Dr Louise Gow, Action for Blind People, oral presentation Vision 2020 (2014)


Kiyana has Down’s Syndrome and regular frames did not fit at her temples and constantly slipped off her face. She is long-sighted and needs to wear glasses. SeeAbility’s dispensing optician found a lightweight frame with an adjustable bridge to fit Kiyana properly.

Kiyana’s mum Dee: “SeeAbility has done a fantastic job finding just the right glasses for Kiyana. She is a different girl now. We have seen a real difference as she is so much more confident”.

Making glasses easy to access for parents/carers was a key finding of the project. Only one parent asked to have glasses dispensed at a community optical practice rather than the school setting. Rachel Pilling (personal communication) found a limitation of the special schools model she used in Bradford was the provision of a ‘prescription only’ for glasses, as once the child had their eyes examined in school, the model required the parents to take the child for glasses fitting at a community optician. She estimated around a third of those who could have benefited from glasses did not follow up.
The impact seen in school

One of the most reported impacts of the project was bringing knowledge of the child’s visual needs to parents, teachers and support staff. It can be the first time in years that anyone has explained to a parent or teacher in layman’s terms just why the child needs glasses, or even what their visual diagnosis means. The other most reported impact was the change in behaviour seen in many of the children who we supplied with glasses. Teaching staff have fed back to SeeAbility that once a child could see better, they seemed happier, more engaged and less likely to exhibit frustration or challenging behaviour.

Nick is a teacher at The Village School.

Nick: “The project has really been a game changer. It is unlocking doors to education, into a social life for my pupils. I can see how my pupils are able to better interact with staff and I am confident that they can now see what they are doing in class.”

Having the continuity of staffing and familiar faces around the school, meant that our team of professionals not only got to know the children but children and staff got to know the SeeAbility team – something that might not happen in a busy hospital or community optical practice environment.

We work with teachers on suggesting font or image sizes for school work, use of technology or where a child should sit in the classroom if they have visual field defects, nystagmus or reduced vision. Working in a special school provides an opportunity to work with those with expertise around the education of children with visual impairment. Of 258 pupils, 109 (42%) were referred to a QTVI. This is a similar finding in the Warrington special schools service, where joint assessments with QTVIs often take place to reach the best decisions for both clinical and educational needs.
In SeeAbility’s experience, even where a child’s visual status is known, the clinical reporting and terminology used in ophthalmic care is not well understood by parents and teachers. The ability to bridge that gap, and explain in layman’s terms what a hospital eye clinic or prescription for glasses actually means can in some cases be the first time a parent has understood what their child can actually see.

**Mani**

Mani (not his real name) had notes in his Education, Health and Care Plan to say that he has a superior coloboma of his iris, lens and retina. For some time this had never been understood by his teachers who reported that moving around school was very difficult - they attributed his raised anxiety and behavioural problems associated with mobility to his autism. SeeAbility was able to explain that the coloboma means that Mani can only see the upper part of his vision, so he can’t see where he is putting his feet or if there is a step, which must make walking extremely frightening, as a consequence when walking he tends to ‘hunch’ right over. Now this has been understood Mani gets more support with mobility and is no longer discouraged from leaning over when he walks.

![What Mani can see due to his coloboma](image1)

![What Mani misses due to his coloboma](image2)

The other impact is on a very practical level, less time out of school for the children who were being seen at hospital eye clinics, meaning less time missed from education.
Rachel Harrison is the Co-head teacher at Willow Dene School, Greenwich

“At Willow Dene we believe in positive partnerships and working together for the best outcomes for our children. We are constantly looking for ways to promote exemplary collaborative working.

To minimise disruption to our children’s education and to make daily life more manageable for child and family we have developed a number of unique school based clinics where visiting professionals conduct their appointments on site. Developing these professional relationships enable us to learn from each other’s expertise and continually improve the provision for Willow Dene children.

As such we were extremely keen to work more closely with SeeAbility to develop an onsite clinic. Their values and collaborative working ethos completely reflect those of the school. Like many special schools we have inherited the legacy of either non-existent or inadequate sight testing. This can impact significantly on the information that we get which helps us make decisions about provision, expectations and the detail of teaching and learning.

Because we are working so closely together with SeeAbility we are now able to learn so much more about what our children can see and make better informed decisions about how to plan their learning. We have seen significant impact, often with our most complex learners, in many cases where glasses have been prescribed and because of this we are seeing a direct link to progress for these children.

The openness of dialogue between school based professionals, the SeeAbility team, children and parents allows the clinics to be conducted in a way which is engaging rather than stressful for the child and parents alike and which is conducive to getting the most accurate results.

We are keen to advocate for SeeAbility’s Children in Focus Campaign as we believe that sight testing is making a tremendous difference here at Willow Dene.”
Improving the model and looking ahead

While SeeAbility considers the service model has worked well, we still recognise there are areas where we need to improve.

One concern was the uptake of the service. The model has to seek individual consent, each year for each child. Next year we aim to work more closely with school nurses, who are key in achieving consent for a variety of medical checks in the school. We need to find out what is stopping parents consenting and if there is any way to identify what eye care these children are receiving, to allow for fuller analysis of the whole cohort of children in special schools.

As with the vision screening programme, and other healthy child programme checks (hearing, weight), there is a strong case to be made for a special schools service to be ‘opt out’ to maximise access to the service amongst a high risk group. This was a key feature of the model used in Bradford (Rachel Pilling, personal communication) and crucially no parent declined to opt out of that service.

Our focus is now turning to the importance of sustaining eye wear, and indeed repeating annual checks. Uptake of repeat specialist sight tests amongst children seen in the first year of the project was not as good as hoped in the second year. We hope that as we train more teaching staff, and improve our communication materials for parents/carers, the number of repeat tests should increase.

We also plan to develop a resource using Makaton to support children to prepare for and successfully take part in a sight test. Another area we will explore is to work with occupational therapists to support children to tolerate glasses, and to expand our engagement with paediatricians.

We also plan to develop our work around transition and embedding vision into the Education, Health and Care Plans for children and in pathways of care once a young person has left special school i.e. providing a ‘vision passport’ for onward communication.

Work undertaken by Judy Bell, Consultant in special education (visual impairment and complex needs), analysing both existing plans and amongst leavers of some of the schools we are working in, demonstrated very clearly that significant information on what the child or young person could see, and wearing of glasses, rarely featured. It cannot be the case that good eye care ends when a child leaves their special school.

To this end, SeeAbility is expanding its work into Trinity School and Sports College in Durham. The school caters for pupils who have a range of special educational needs including moderate learning difficulties, severe learning difficulties, communication disorders (including specialist autistic provision) and complex and multiple learning difficulties. Working in a different geographical area will provide interesting and
complementary data to our work in London schools. The area is developing its own LOCSU pathway for adults with learning disabilities\(^{23}\) – to ensure young people and adults are able to access sight tests that are reasonably adjusted (eg. additional time at the optical practice, trained staff, use of easy read information) in their local community. This will provide young people leaving the school with a service that SeeAbility can refer them on to.

In 2016 we are also excited to begin working with Heritage House, a special school for children with severe, profound and multiple disabilities in Buckinghamshire, and with Charlton Park Academy in Greenwich, a secondary school which Willow Dene pupils will often move on to - therefore helping us to continue to see the children we have already been working with.

SeeAbility also recognises that we need to undertake further work around demonstrating outcomes. We would welcome the opportunity to work closely with schools and with NHS England and contribute to a more comprehensive piece of research on the reduced carer burden and the improved educational outcomes associated with sight testing in special schools. We also plan to update our calculations on the cost of the SeeAbility model, as this year we extended input from orthoptist and dispensing opticians.

Finally, there is no specialist qualification for eye care professionals working with children with learning disabilities. This is a gap that needs to be filled if a special schools service is to become a reality across the country. SeeAbility is now making plans to work with others to fill this gap.

**A word about the General Ophthalmic Services (GOS) contract**

SeeAbility also hopes that in becoming a GOS contractor, it is helping NHS England understand how the current GOS model could work more flexibly for children with special educational needs. It is clear the legal, contractual and funding framework for NHS sight tests is not designed for children with complex needs. Currently the NHS pays a flat fee of £21.31 per sight test in a special school – the same as is paid for any ‘standard’ community sight test.

Certainly the awarding of the contract provides an opportunity for a case to be made to refine the operation of GOS. For example:

- Clarity on what is required under GOS where elements of the test may in fact be too distressing or intrusive for some children to be completed. For example, a good fundal view of the back of the child’s eye may not always be possible because it causes excessive distress.

- The application of GOS rules on glasses.\textsuperscript{24} Spares are allowed under guidance – if a child with a disabling illness is breaking his/her glasses with such frequency that his/her education is being disrupted. In one NHS England regional policy – the frequency is interpreted as 2 or more repairs in the preceding 6 months but the SeeAbility contract will certainly put this to the test.

- In addition GOS currently does not provide vouchers for frames for special facial characteristics, while the hospital eye clinic system does, adding complexity to an already complex system. It is hoped these rules may change soon.

\textsuperscript{24} The National Health Service (Optical Charges and Payments) Regulations 2013
Conclusion

SeeAbility wants specialist sight tests and glasses dispensing to be available in every special school in England. By focussing on a population of around 100,000 children in England 25 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 of children that are in real need of a reasonably adjusted model of care. Our work and that of others shows that a special schools service can work in practice.

In February 2016, the Welsh Assembly Government published its plans26 for a dedicated, nationwide special schools sight testing service in Wales. The onus is now on the Department of Health and the NHS to follow suit in England.

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. Separate negotiations with over 200 local health commissioners to fund a special schools service in their areas will not deliver an equal right to sight for children with learning disabilities – the variability that currently exists in the delivery of eye care in special schools is testament to this.

The model supports the move towards preventative, early health care, which includes preventing unnecessary sight loss. There is a need for the NHS to find more financially efficient ways of working, to transform care so it is closer to home and to reduce pressure on hospital Trusts. By addressing the health inequalities that children with learning disabilities and/or autism experience, and by bringing health and education together, a national programme could improve outcomes for children with special educational needs and in so doing support their family carers too – for example by reducing the need for hospital visits.

A special schools sight testing service 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 risk of sight problems in this group of children; improve access to mainstream services and vision checks for children and young people not at special schools or transitioning to adulthood; enable data collection on access to eye care and outcomes from it for children with learning disabilities; and ensure eye care and vision information is a key part of a child’s special educational needs plan, appropriately shared between health and education.

25 See Glossary of this report for more information.
26 See School Pupil Eye Care Services (SPECs) Consultation ending 2 May 2016. www.eyecare.wales.nhs.uk/specs-consultation
What are special educational needs or ‘SEN’?

According to the statutory government code of practice\(^{27}\), children with special educational needs or ‘SEN’ all have learning difficulties or disabilities that make it hard or harder for them to learn than most children of the same age. This might include needs around behaviour and interaction, speech and language, sensory impairment, cognitive difficulties or physical disabilities.

What is a special school?

Special schools can be defined as:

“A school which is specifically organised to make special educational provision for pupils with SEN. Special schools maintained by the local authority comprise community special schools and foundation special schools, and non-maintained (independent) special schools that are approved by the Secretary of State under Section 342 of the Education Act 1996.”

(Department for Education and Department of Health, 2014)

Special schools and pupil numbers in England

There is no publicly available list of special schools (which may include schools that are independent schools). Following a Freedom of Information request, in March 2015, the Department of Education provided SeeAbility with a list confirming 1581 special schools in England.

Pupil numbers are published in government figures.\(^{28}\) Overall there are 103,595 pupils in special schools. However this does not include pupils in independent special schools or post-16 specialist colleges. In independent special schools there are at least 11,700 pupils.\(^{29}\) The Department of Education has confirmed to SeeAbility it does not collect the primary SEN needs of children in independent schools (eg. autism, profound and multiple learning disabilities).

Using the published figures, nearly 80,000 pupils in special schools (excluding independent schools or post-16 specialist colleges have a primary special educational need of a learning disability, autism or sensory impairment.

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\(^{27}\) Department of Education and Department of Health. SEND Code of Practice: 0-25 years (2014)  

\(^{28}\) Department of Education Special educational needs in England: January 2015 Table 5. See the following link  

\(^{29}\) This is from SEN statistics team underlying data at the website above.