

Children in Focus Campaign

Third year annual review (2017)



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

Telephone: 01372 755 000 Website: www.seeability.org/childreninfocus

Email: childreninfocus@seeability.org

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

Photo overleaf: SeeAbility dispensing optician Ned Saunders with Ella, at The Village School

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 standard practice in special schools in England.

The programme of specialist sight tests¹ to pupils in a number of special schools and the findings have been evaluated by Cardiff University's School of Optometry and Vision Science.

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 SeeAbility's third annual report about the service findings.

Key findings

The third year of data reinforces the findings from the first and second year of testing. This year, data has been evaluated from when the service started in October 2013, covering three full academic years of sight testing. This is a larger cohort of children with which to gain an understanding of the eye care needs of special school pupils. The average age of children tested was 10.39 years.

The service evaluation from SeeAbility's Children in Focus Campaign continues to demonstrate that almost all children can have a specialist sight test if they feel prepared and a personalised approach is taken. This is especially important given the service continues to highlight that children with autism in special schools are more likely to have had no history of eye care.

Across the three years course of the service we have found:

A high level of sight problems

- Half of children we tested (47.4%) have a problem with their vision, so the scale of need is evident.
- Around one quarter of children for whom we could get an accurate measure have such poor sight to be classed as 'low vision'.

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*).

- A third (31.1%) of children need a spectacle correction. There are also high levels of prescription needed and over a quarter of pupils have some type of squint or eye movement anomaly.

Few children accessing their right to a community eye test

- 4 in 10 children (nearly 42%) have no history of eye care. There was little change to this even amongst children of secondary school age.
- Few children (7.1%) access a community optician although this is where most children are expected to exercise their right to a free NHS sight test.
- Over half of children (50.3%) have or were having their eye care in hospital.
- Even children with known sight problems are not accessing community alternatives once discharged from a hospital eye clinic. Overall 85% do not report any further eye care once discharged.

Serious sight problems have been newly identified

Most striking is that 13% - nearly 100 pupils - we have seen over the course of the service had a vision problem that was previously unknown to school or parents.

Around 6% of pupils have an optical problem that needs onward referral to a GP or for hospital treatment. Some of these can be serious, potentially blinding conditions if not identified, such as keratoconus or cataract. Other problems were managed in school because the service benefits from the input of an orthoptist, again highlighting the benefit of a multidisciplinary model and mechanisms that allow for co-ordination with local hospital services.

Even squint (where the eye turns) and refractive error (e.g. long or shortsightedness) can have a significant impact on a child's education and development, their social skills and behaviour, and may lead to permanent sight loss if allowed to go untreated.

There is a high need for spectacle support

We are also able to highlight the benefit of spectacle support in school, and although 31% of children need spectacles, this is not just a case of straightforward dispensing. Children often needed specially adapted frames (e.g. when they use a headrest on a wheelchair) or strong frames (e.g. when they exhibit behaviour which challenges) and good fitting is critical when children may be unable to effectively communicate discomfort. Our dispensing optician is frequently called upon to help repair and fix spectacles, and support children to get used to their spectacles.

As 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 special educational needs. Given some children are non-verbal or may rely on their eyes to communicate (e.g. using eye gaze technology), being without spectacles is also going to have a significant impact.

The school environment is key

The calm, familiar setting in their school, with trusted staff and peers around them, relieves stress and anxiety for children and means they are much more likely to comply with a sight test and get used to eye care as they become young adults. The other reported impact was the change in behaviour seen in many of the children who we supplied with spectacles. Once a child could see better, they seemed happier, more engaged and less likely to exhibit frustration or challenging behaviour.

School services bring greater flexibility to re-schedule or carry out different elements of the tests on different days/at different times without any need to take the child out of school. Working in a special school also provides an opportunity to share information in layman's language with parents and give immediate feedback to teaching staff to support a child to maximise their vision in school.

Other developments this year

While we continued to work in six special schools we expanded during the school year to two more schools, and engaged in a short term pilot in a school in Durham.

We worked hard to gain greater uptake of the service this year, which now covers 70% of pupils across these schools. Behind the scenes we have also published new materials to bring better, more understandable information about eye care to children, parents and teaching staff. Over the course of the service we have also trained 373 teaching assistants and support staff, and presented/exhibited at 7 conferences just this year.

Next steps

National optometric and learning disability programmes have so far overlooked the needs of people with learning disabilities in terms of adequacy of optical funding and promotion of good eye care. Currently the NHS pays a fee of £21.31 per sight test in a special school – the same as is paid for any 'standard' community sight test. This is a growing group of children and it is clear from the data that eye care for these children is primarily delivered in hospitals, sometimes because there is no community alternative. This is potentially a more expensive setting for eye care to be delivered.

The model provides an efficient way of working, helping reduce avoidable use of under pressure hospital eye clinics by providing an alternative setting for eye care. The value of having a multidisciplinary team with orthoptic input and dispensing expertise provides a 'one stop shop' of support and reduces fragmentation.

SeeAbility would like to see NHS England develop a properly funded national programme of specialist sight tests in special schools. 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.

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 information about eye care and vision on our website including easy read factsheets about sight tests, different eye conditions, and treatments, videos, and details of optometrists who can support people with learning disabilities to have an eye test and access good eye care. See: www.seeability.org/looking-after-your-eyes

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 and Dr Maggie Woodhouse, Principal Investigator for the project, Cardiff University School of Optometry and Vision Science for analysis of the data.

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. The schools involved are:

School	Age range	Total number of children at the school
The Village School	4-19	268
Lower Perseid	3-11	80
Upper Perseid	11-19	80
Moorcroft	11-19	65
Grangewood	3-11	100
Willow Dene	3-16	208
Heritage House	2-19	73
Charlton Park	11-19	193
Durham Trinity (* pilot)	2 – 11 (primary school age only although school supports 2 -19 year olds)	88

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

The Alf and Hilda Leivers Charity Trust
The Bloss Foundation
Candis Club
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Greater London Fund for the Blind
The Hospital Saturday Fund
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Mr E Herd
Mr and Mrs J Moulding
Mr and Mrs N Wagstaff
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Optix
Rutland Partners
Sir Jeremiah Colman Gift Trust
Sir William and Lady Wells
The Steel Charitable Trust
UKH Foundation
Worshipful Company of Lightmongers
Worshipful Company of Spectacle Makers' Charity
Wyvern Partners

About our NHS contract

SeeAbility has also secured a NHS contract to help part fund our work in providing each special schools sight test. However the NHS only pays a flat fee of £21.31 per sight test – the same as is paid for any 'standard' community sight test. The NHS also provides some funding (via 'vouchers') towards the cost of spectacles when they are needed.

We are helping NHS England understand how their current contractual model with optometry services could work more flexibly for children with special educational needs. It is very clear that the funding framework is not designed for children with complex needs and the report goes on to discuss reforms needed.

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 tests³ are standard practice in special schools in England.

This is a report about our third year findings which includes externally evaluated clinical data for the academic year September 2015 to July 2016. The first and second year reports of the Campaign can be found at www.seeability.org/childreninfocus.

This year our report also reflects upon:

- Clinical data from when the service started in 2013, based on 719 pupils who were new to the service up to July 2016, to help build up a bigger picture of eye care needs of children in special schools.
- The work of our dispensing optician, fitting and fixing spectacles, and supporting children to continue to wear their spectacles, which is a key part of the service model.

Visual impairment and blindness is relatively rare in the general population of children⁴, but SeeAbility estimates that children with learning disabilities are 28 times more likely to have a serious sight problem based on current research. The incidence of visual problems is also growing as this group of children grows, due to the increased survival rate of preterm babies, who have a higher risk of visual problems and disability.⁵

The report discusses the types of sight problems found in children with learning disabilities and where possible this report will use layman terminology, rather than clinical, for ease of understanding.

Many sight problems are both preventable and treatable, so early eye care is essential. Eye problems that remain undetected, such as squint (where the eye turns), longsightedness, shortsightedness and astigmatism, may lead to reduced vision - also known as 'amblyopia' - which, if untreated, can result in permanent damage, even the permanent loss of vision in the worst cases.

³ 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.

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 (Emerson and Robertson, 2011, *The estimated prevalence of visual impairment among people with learning disabilities in the UK*).

⁵ Salt, A and Sargent, J (2014) "Common visual problems in children with disability". Archives of Disease in Childhood. 99:1163-1168.

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. However information on a child's visual needs does not always reach parents or teachers in an understandable format.

Children in full time education have the right to a free NHS sight test and spectacle vouchers if needed, but years one and two of SeeAbility's Children in Focus Campaign and other studies in special schools⁶ have confirmed that children with learning disabilities are highly likely to have undiagnosed or untreated sight problems, and are also less likely to get access to the eye care they need.

There are a number of reasons why children with learning disabilities miss out on their right to a sight test, and this is discussed in SeeAbility's report 'An equal right to sight', published in September 2015.⁷ There are only a few areas of the country where specialist eye care support is offered in special schools at all ages.

⁶ For example, see 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 and 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

⁷ 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

Reflections on the past year

This review looks back at an important and busy year for the Children in Focus Campaign, with the sight problems experienced by children with learning disabilities continuing to gain national attention and our work developing in a number of ways.

Schools work

While we continued our work in six special schools we also expanded during the school year to three more special schools.

New schools involved were:

- Charlton Park Academy, a secondary special school South East London, from January 2016.
- Heritage House, in Chesham, Buckinghamshire from February 2016.
- A short term pilot was also linked to a community optical practice, which provided sight tests at Trinity School and Sports College, Durham.

Last year's annual report reflected upon a need for greater uptake of the service amongst pupils in existing schools we were working in, as average uptake was 39% amongst all pupils. A programme of re-consenting pupils into the service has been conducted and uptake is now at 70%.

During the school year SeeAbility also offered training for all staff on the principles of eye care and vision in children with learning disabilities. To date over the past three years we have trained 373 learning and support assistants and teachers to support the new school programmes.



Training at Moorcroft School

To also assess satisfaction with the service this year, a survey monkey was created for staff in the schools to complete electronically. 34 were completed.

- 100% rated eye care received as good/excellent
- 97% rated the information received about vision as good/excellent
- 72% said they now know and understand more about vision

New resources

With Ulster University's Vision Science Research Group we have developed a report we are using to explain the results of an eye examination in plain English, non-medical terminology. The report is designed to explain how a child sees, their visual limitations and abilities and to suggest strategies to maximize their visual potential. We also published a new resource for children who are Makaton users, to help them understand what is involved in a sight test through signs and symbols.

We revamped a range of downloadable resources on our website 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. More information on these resources can be found here: www.seeability.org/eye-tests-children

New projects and professional dissemination

We started work with the Whole Child Therapy team of Occupational Therapists, focussed in one school, The Village School. The aim of this project was for the team to work with our dispensing optician and test ways in which to support children to tolerate and get used to wearing their prescribed spectacles. The Occupational Therapists carried out sensory processing assessments with a group of 10 children who were struggling to wear their glasses. They devised strategies to try to integrate their new view of the world into their whole sensory experience.

Some of the successful strategies included encouraging glasses wear whilst active when all the senses are stimulated, such as on a trampoline or in a swing. Our dispensing optician is now starting to share this knowledge across all the schools. We are also working on a resource which we can share widely, based on these strategies.

We have explored and developed relationships with other members of the school health and education teams – e.g. Occupational Therapists who can support children with adaption to spectacles and Speech and Language Therapists for ensuring spectacles are used when needed for Eye Gaze communication tools.

We continued to bring together professionals from across the health and special education needs sector to discuss development in practice and presented and exhibited at 7 conferences for paediatricians, qualified teachers for the visually impaired, visual impairment staff, teaching staff, dispensing opticians, orthoptists and optometrists. This

included workshops around the needs of people with a learning disability at three of the annual national optical conferences.

Recognition of the innovative work we are doing came when Ned Saunders, SeeAbility's dispensing optician for the special schools service, won the hotly contested Dispensing Optician of the Year award at the 2017 Optician Awards. He was nominated along with four other opticians, who were selected by a panel of experts specialising in different areas of optometry and the optical industry.

Publication of a recommended clinical framework

As highlighted last year in our second annual report, SeeAbility began working with a task and finish group⁸ to develop a framework for provision of eye care in special schools that would set out the clinical recommendations for these services and a recommended pathway for treatment. We were very grateful to all the professional bodies and their representatives for their support for this work. The group sent its recommended framework to NHS England in May 2016.⁹

Working on national change

We were delighted when regulations preventing people with learning disabilities from conveniently accessing special facial characteristic frames in community optometry were changed. This inequality was highlighted by local Durham optometrist, Simon Berry, who engaged the support of his local MP, SeeAbility and the Down's Syndrome Association.

July 2016 also saw the launch of SeeAbility's new report called *Delivering an equal right to sight*,¹⁰ discussing the eye care needs of both children and adults with learning disabilities and how the NHS England sight testing system needs further reform in order to meet those needs. The report, with a forward by Lord Holmes of Richmond MBE, was launched at an event in parliament.

This activity resulted in NHS England policymakers, the optical sector and learning disability representatives beginning a programme of work to examine the case to transform eye care for people with learning disabilities. Specifically the project is looking in detail at SeeAbility's call for a new national programme of sight tests in special schools in England.

Parliamentarians continue to take a real interest in our work and we were also pleased to host visits during the year for Barry Gardiner MP, Rt Hon Cheryl Gillan MP and Dr Roberta Blackman-Woods MP, who all came to visit the service in their constituencies.

⁸ The group were formed of 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). Representatives of the Children's Vision Service Advisory Group in Wales also advised this group, as plans have been issued by the Welsh Government for special schools in Wales

⁹ The framework paper can be found here: www.seeability.org/Handlers/Download.ashx?IDMF=f3c1194b-512e-41a4-844d-b564222ad84d

¹⁰ For the full SeeAbility report please see www.seeability.org/equalrighttosight

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 on spectacles, and release more of optometrist time (as they were previously also fitting and dispensing spectacles) for the specialist sight testing. The dispensing optician is also able to act as a chaperone at the sight test. The day to day operation of the service is managed by our Optometry Practice Manager.

- Dispensing opticians are registered professionals who fit and supply spectacles and visual aids. Under current legislation, only dispensing opticians or optometrists may supply and fit spectacles to children under 16 or anyone registered as sight impaired or severely sight impaired.
- Orthoptists investigate, diagnose and treat defects of binocular vision and abnormalities of eye movement.
- Optometrists examine eyes, test sight, detect eye disease or abnormality, prescribe spectacles and give advice on visual problems and/or treatment.

All children are seen jointly by an orthoptist and an optometrist at age 4-5 years (school entry). All other eye tests are carried out by the optometrist who can request an opinion from the SeeAbility orthoptist in school where needed.



The Children in Focus team

Prior to commencement of the service, discussions will have taken place with local ophthalmic and paediatric services and schools to ensure the service is needed. Not every area has the same structures or referral mechanisms so we tailor the model to local circumstance. The tests undertaken, and the equipment used in the project can be found in our first and second annual reports www.seeability.org/childreninfocus.

The term 'specialist sight test' has no legal meaning – it is used 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 and is a recommendation in the task and finish group framework.

Parents/carers who opt for their child to be given a specialist sight test in school, are given 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.

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 classroom or even the playground, if appropriate.

Parents are asked if they wanted the team to fit spectacles or are given the option of taking a copy of the prescription (and corresponding voucher amount) elsewhere for dispensing.

The SeeAbility team work with children to help them get used to their spectacles and provided specialist or flexible frames, bespoke adaptations, straps, adjustments, repairs and replacement spectacles as needed. There is a routine 3 month follow up by the dispensing optician with each child prescribed spectacles for the first time to identify any problems with the spectacles and provide support around getting used to wearing them.

If there were concerns about a child's vision or eye health which warranted further investigation, referrals were made onwards to the GP or the hospital eye clinic as appropriate. Results of the specialist sight tests are 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'. The form explains the findings of the examination in a clear way and gives an action plan.

Potential visual problems and the need for spectacles can 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 are also provided with a leaver report summarising what has 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.

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

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.

This section of the report includes analysed data for the academic year September 2015 to July 2016.

Numbers of pupils who had a sight test in 2015 - 2016 academic year

Overall **481 pupils** were seen in total in 9 schools.

35 of 481 pupils had full episodes more than once during the academic year, making 516 examination episodes altogether.

This means that 7% of pupils needed more than one examination in the same year as it was clinically justified.

As the Trinity pilot did not cover our usual reporting period of the academic year (the pilot took place across two terms of April – November 2016), this report sets out the separate pilot findings in a later section so readers can understand the differences in this pilot.

Therefore the following analysis is for **427 pupils across 8 schools**, excluding Trinity.

Ages and noted diagnosis of pupils who had a sight test

Ages ranged from 2.58 to 19.75 years.

Around 44% of children had autism noted on their records, 15% were noted as having cerebral palsy, while 7% had global developmental delay noted. The remaining 34% of children had a range of complex needs, often multiple diagnoses or rarer syndromes.

These are not 'formal diagnoses' or comprehensive - this information was based on the forms we collected from the parents/carers 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

There were 253 new children using the service. We asked parents/carers for previous history of eye care on the forms we gathered from the new children.

Reported history of previous eye care was available for 229 pupils.

- **43.7% (100) had no history of previous eye tests**
- 26.2% (60) had been seen by hospital eye services and discharged
- 24.0% (55) were currently under hospital eye services
- 6.1% (14) had no hospital eye service history but had been seen by a local optometrist (this includes 3 cases where a child had been seen by an optometrist in their school – prior to the SeeAbility service beginning).

To summarise, the majority were not receiving any eye care at all and very few children reported accessing a community optician.

Autism

Pupils with autism were more likely to have no history of eye care (75 of 113) than pupils with other diagnoses (21 of 102) which was statistically significant (Chi squared 45.47, $p < 0.001$).

Of the 100 children with no history of eye care, 75% (75) had autism.

Level of refractive error

Refractive errors are optical imperfections that prevent the eye from properly focusing light, causing blurred vision. The primary refractive errors are longsightedness (also known as hyperopia), shortsightedness (also known as myopia) and astigmatism – this is where the cornea or lens of the eye isn't a perfectly curved shape.

Outcomes for the whole cohort of pupils of 424 pupils were:

- 21.2% (90) of pupils were shortsighted
- 25% (106) were longsighted
- 32.3% (137) had astigmatism (Please note astigmatism can co-exist with long or shortsightedness hence total >100%)

In ophthalmic care, the degree of focussing (refractive error) is measured and recorded in units called dioptres illustrated by the letter 'D'. The higher the number measured in dioptres, the higher the refractive error and therefore the greater the blur experienced if refractive error is not corrected.

This year refractive errors ranged from extremes of -18.75D to +14.50D. In either case the child would be severely visually impaired without spectacles.

Not all children will need spectacles, but across the cohort of new and repeat pupils seen this year 38% needed spectacles.

Spectacles dispensing

Outcomes were available for 251 new pupils. This year of new pupils seen **33% (82) needed spectacles.**

Of these 251 pupils 20% (50) required spectacles for the first time or a change of prescription, the remainder no change in their current spectacles or needed replacement for fair wear and tear.

Parents were offered the choice of taking a copy of the prescription (and corresponding voucher amount) elsewhere for dispensing, however all parents requested their child had their spectacles dispensed at school.

The figures above do not reflect the 'true' level of interactions with the dispensing optician or level of need. In effect the dispensing optician has more interaction with pupils than the optometrist. This is because the dispensing optician sees all children 2-4 times (once to dispense, then again to supply and fit then 0-2 further follow ups at 4-12 weeks to assess fit and adaption/make adjustments.

We estimate about two thirds of children need repairs, refits, and adjustments. All of our fittings and around half of our dispensing appointments were carried out in the classroom, soft play, music room etc.

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.¹¹

It is assessed as the child 'presents' at the sight test, in other words if they come with or without their spectacles 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. It can be challenging to reliably record visual acuity in children with learning disabilities, which is reflected in these findings.

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

¹¹ The tests used here were Keeler cards, Cardiff Acuity Test and Kay's singles, all considered non-crowded, and the Kay's crowded test.

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.

New pupils

Presenting best acuity was available for 132 pupils. Acuity was not always possible due to the limitations of currently available tests for this group of children.

Where we were able to measure vision, **25% (33) newly seen pupils had low vision**¹² according to the World Health Organisation (WHO) criterion (LogMAR 0.5 or poorer in the better eye), including 7 with acuity of LogMAR 1.0 or poorer and 1 pupil with light perception only.

All children tested this year

Altogether across the whole cohort of pupils (427 in total), 231 were able to participate in visual acuity testing. **26.8% (62) had low vision.**

Other clinical findings

Squint and overall orthoptic anomalies

Orthoptic anomalies and squints are conditions affecting the ability of the eyes to move and work together. A squint is present when the two eyes are not in alignment with each other; it is often treatable with spectacles but may require surgery. Uncorrected squint usually results in reduced vision in the affected eye (amblyopia) which can be treated with glasses and/or patching of the better eye. In addition, squint and other orthoptic anomalies may give symptoms of blurred vision, double vision, lack of depth perception, inability to accurately find or follow an object with the eyes or move the eyes into certain positions.

Another condition is nystagmus, which causes constant movement of the eyes which can't be controlled.

32.8% (140 pupils of 427) had an orthoptic anomaly (excluding phoria¹³).

118 of the pupils had a squint and 22 had an eye movement disorder (please note for pupils recorded in the nystagmus category this took precedence over squint).

Other ocular disorders

Separately, eye abnormalities or other eye health issues were recorded in 19 cases, ranging from 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.

¹² The World Health Organisation full definition of low vision can be found here <http://www.who.int/blindness/causes/priority/en/index4.html>

¹³ A phoria is a misalignment of the eyes that is usually controlled.

We were able to diagnose three teenagers with keratoconus and refer them on to hospital for further investigation and potential treatment. This is a progressive disease of the cornea - the front surface of the eye - in which vision deteriorates over time as the cornea becomes increasingly distorted.

Other cases either required no treatment or could be managed in school, sometimes with the support of the GP (for example, a prescription for drops to treat conjunctivitis, or instructions on lid cleaning for blepharitis).

Suspected Cerebral Visual Impairment

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 and we use a screening questionnaire to identify possible cases. We suspected CVI in 14% (60) children seen this year.

Referral to QTVI

Of the 427 pupils seen this year 200 pupils were referred to the QTVI – representing 46.8%. In particular the referrals were for:

- 30 children for suspected CVI
- A further 30 children for suspected CVI and another condition
- 131 children were referred for other conditions resulting in visual impairment, such as ocular pathology, nystagmus or prescription spectacles

Other referrals

Of the 422 pupils seen this year for which outcomes were recorded:

- 1.4% (6) were referred to hospital eye services
- 1.2% (5) were referred to their GP
- 3.8%(16) were referred to the SeeAbility orthoptist

Previously undiagnosed vision problems

Diagnosis in terms of any form of visual deficit was available for 252 pupils

- **14.7% (37) had a vision problem not previously known to the school or parents.**

Of the 100 pupils who had no previous eye care:

- 11% (11) required spectacles and 8 of these children had significant refractive error:
 - 4 had significant astigmatism (2.00 to 4.00DC)

- 3 had significant longsightedness (4.25 to 8.00D)
- 1 had significant shortsightedness (-4.00D)

- There was also a need to refer 5 children for investigations (1 was referred to hospital eye services, 1 to their GP, 3 were referred to the SeeAbility orthoptist).
- 10 children had low vision (although not all children could have visual acuity recorded), including 1 with acuity poorer than LogMAR 1.0 – meaning 30% of children with low vision had no history of eye care.
- 16 pupils had a visual deficiency that was not previously known to school or parents and 2 pupils (2%) had a visual problem already known but had not been treated yet. Both of these were squints (although the pupils had never attended hospital eye services). One of these children also had a significant refractive error and was prescribed spectacles by SeeAbility.

Durham Trinity School and Sports College pilot

The Durham Local Optical Committee (LOC) together with Durham Dales, Easington and Sedgfield CCG and North Durham CCG have jointly set up a pilot service to enable people with learning disabilities to gain better access to eye care in both of these CCG areas. It was felt that a pilot in a special school in the area could help complement this work and help children transition into using the new pathway. This pilot ran from April – November 2016. With support from the Local Eye Health Network SeeAbility worked in partnership with the orthoptic team from University Hospital of North Durham and employed a local optometrist and optical assistant from Simon Berry Opticians. Simon Berry is a very experienced optometrist whose own practice has set up a clinic for people with learning disabilities.

A training day was delivered by SeeAbility to all 62 teaching and support staff in the school prior to the start of the project around eye care and vision. All rated their knowledge of eye care as low prior to the session and higher at the end, many hadn't realised that eye tests were possible for children with complex needs.

This service was offered to 88 primary school children up to age 11. 56 sight tests were completed (65% of all children offered a test) by the end of the pilot.

- 48% of the pupils seen (27) had no reported history of any previous hospital or optometric care which was higher than expected.
- 17 pupils (30% of total seen) had a history of hospital eye care services. 12 pupils having been discharged and 5 pupils still under hospital eye care.
- 13 pupils (22%) had previously been to a community optical practice for an eye test.
- 6 pupils (11%) were prescribed a first pair of spectacles and 2 a changed spectacle prescription. 16% of all pupils seen needed spectacles. The school reported that across the whole school population 38.5% of pupils already wore spectacles.

Only 25% of parents chose to have their child's spectacles dispensed and supplied in school – compared to 100% in the London schools during this period. 3 pupils (5%) were identified for the first time as having suspected Cerebral Visual Impairment and were referred on for further ophthalmological and QTVI (Qualified Teacher for the Visually Impaired) support. All those requiring further follow-up were referred into hospital eye care at the end of the pilot.

Respondents rated the service as excellent and when asked to state their preferred location for a sight test for their child all parents responding chose the school setting. All anecdotal comments about the project were positive from the school. Recommendations for the Local Eye Health Network is to assess unmet need locally with a view to commissioning more appropriate services going forward, make use of special schools for hospital reviews and to distribute information on vision and eye care to all special schools/improve communication between eye care services and education.

Findings since SeeAbility service began

Over three school years from October 2013 to July 2016, SeeAbility has conducted **905** full eye examinations in nine special schools, and this report provides an opportunity to provide some overall analysis. We have tested children aged 2.58 years to 19.75 years and the mean age of children we have tested is **10.39 years**.

719 pupils were seen for the first time, the remainder being follow-up annual visits.

The following analysis applies to pupils seen for the first time by SeeAbility (Please note sometimes the percentages do not total exactly due to rounding.)

Previous history of eye care amongst new children to the service

Parent reported eye care history was available for 636 pupils:

- **41.7%** (265 pupils) had no previous eye care
- **50.3%** (320 pupils) had been seen by hospital eye services; 154 were currently hospital outpatients and 166 had been discharged. Of the 166 discharged only 24 (15%) of these children had gone on to see a community optometrist, meaning 85% had no further eye care after discharge from hospital eye services.
- **7.1%** (45 pupils) had some record of eye tests at an optometrist practice.

1% of pupils had been seen at school on referral by a paediatrician.

Vision problems overall

Data on final conclusions about visual defects were recorded for 711 pupils.

47.4% (337 pupils) had some form of visual deficiency.

Numbers needing spectacles overall and refractive error

A total of 146 pairs of spectacles were dispensed, including 97 first time corrections.

31.1% (223 pupils) needed spectacle correction in total.

13.5% (97 pupils) were prescribed spectacles for the first time, 5% (36 pupils) required a change of prescription, 1.8% (13 pupils) required replacement for fair wear and tear, 10.7% (77 pupils) had adequate spectacles and 4 pupils were advised to discontinue.

Altogether looking across the whole cohort of pupils, of 703 pupils with successful refractions¹⁴:

¹⁴ Using the same criteria for refractive error as other studies. In particular 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) in a large, multi-racial sample of mainstream school children

- 22.3% (157) had shortsightedness (equal to or more than - 0.50D in either eye)
- 16.4% (115) had longsightedness (equal to or more than +2.00D in either eye as long as one eye is not shortsighted)
- 31.6% (223) had astigmatism (equal to or more than 1.00DC in either eye)

Visual acuity and accommodation

433 pupils were able to participate in visual acuity measurement. The remainder of pupils were uncooperative for acuity testing, and over half of those children who were uncooperative (56%) were noted as having autism.

28% (129 pupils) had vision too poor to allow acuity testing, or had low vision according to the WHO criterion (LogMAR 0.5 or poorer in the better eye).

How many children would 'fail' a vision screening test?

In the UK, the National Screening Committee recommends vision screening of children at school entry, age 4-5 years. The recommendation is that a LogMAR test is used, and if a child cannot see a certain level of detail with each eye separately or they are unable to perform the test, they will be referred on for further, fuller tests dependent on local protocols.

To give sufficient numbers for analysis, data was selected on the 4-7.9 year age group and determined whether each pupil would pass or fail vision screening.

Of the 264 pupils in this age group, only 25 would pass vision screening – meaning over **90% would fail**. Across the entire age range, only 160 of the 719 pupils would pass vision screening; 77.7% would fail.

Accommodative accuracy was also recorded for 563 pupils. Accommodation is the ability to shift focus (ie. flex your natural lens inside your eye). 10.9% (59 pupils) had under-accommodation and 1.1% (6 pupils) over-accommodation. The result was inconclusive for a further 9.4% (53 pupils).

Squint and overall orthoptic anomalies

Presence/absence of an orthoptic anomaly was recorded for 670 pupils.

- **24.8%** (166 pupils) had squint (with or without another eye movement anomaly).
- 1.5% (10 pupils) had nystagmus (involuntary eye movements)
- 1.0% (7 pupils) had both strabismus and nystagmus
- 3 pupils had another eye movement anomaly.

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.

Ocular (eye health) disorders

Presence/absence of ocular disorders was recorded for 719 pupils.

5.9% (43 pupils) had an ocular anomaly ranging from mild blepharitis, to keratoconus (4 pupils), cataract (8 pupils) and retina/disc abnormalities (17 pupils).

Unidentified need and referrals onwards

12.9% (92 pupils) had a visual deficiency that was previously unknown to school or parents.

This included 14 cases of low vision and 29 cases of uncorrected high refractive error (9 cases of shortsightedness between -3.00D and -18.00D, 5 cases of longsightedness between +4.00D and +10.50D and 15 cases of astigmatism between 2.50 and 4.50DC).

2.3% (17 pupils) were referred to hospital eye services, 0.8% (6 pupils) to their GP and 3.3% (24 pupils) for orthoptic review. The latter were older pupils who we had picked up with concerns and could be referred to the SeeAbility orthoptist in school.

Of 719 children, 23 needed to be referred on for eye care 'outside' of school – a 3% referral rate. 260 pupils (36.2%) were referred to the QTVI as new cases.

What is the eye care need amongst older children?

Cardiff University also audited the level of need amongst the older age group of children SeeAbility had seen over the past three years. Breaking the data into primary and secondary school age groups showed a significant change in numbers of children with shortsightedness (Chi squared = 6.35, $p = 0.042$) as children got older.

- shortsightedness 19.1% and 26.8% respectively
- longsightedness 17.9% and 14.8% respectively

High shortsightedness (more than -6.00D in either eye) was recorded for 15 secondary age pupils.

Of 267 secondary school age children with recorded history, 39.3% (105) had no history of eye care, 49.4% (132) had been seen by hospital eye services; 43 children (16.1%) were still under hospital eye services.

9.7% (26) pupils had been seen by community optometry only. Of 89 pupils discharged by hospital eye services, 18 had then gone to a community optometrist. 4 pupils had been seen in school by an optometrist.

Discussion

The third year of data reinforces the findings from the first and second year of testing. What the service shows is that almost all children can have a specialist sight test if they feel prepared and a personalised approach is taken. This is especially important given the service continues to highlight that children with autism in special schools are more likely to have had no history of eye care.

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 spectacles wear.

Half of children have a sight problem

Across all three academic years we now have data on a larger cohort of children, and overall nearly half of children we tested (47.4%) have a problem with their vision, so the scale of need is evident.

And around one quarter of children for whom we could get an accurate measure have such poor sight that they can be classified as having 'low vision'. Some will have problems with processing their vision known as 'Cerebral Visual Impairment'.

The data also confirms that 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.

Few children go for a community eye test

Despite this level of need, the evaluation confirms a large proportion of children in special schools (4 in 10) have no history of eye care. There was little change in this even amongst children of secondary school age.

It appears very few children (7.1%) access a community optician, although this is where most children are expected to exercise their right to a free NHS sight test.

In the most part, around half of children have or were having their eye care in hospital. This brings associated challenges of time out of school, travel to hospital and potentially stressful waits in an unfamiliar clinical environment. Some parents reported their children had been refusing to attend hospital eye clinic appointments because of the anxiety it can provoke.

It is also clear that even children with known sight problems are not accessing community alternatives once discharged from a hospital eye clinic. Overall 85% do not report any further eye care once discharged.

Serious sight problems have been identified

Most striking is that 13% - over 90 pupils - we have seen over the course of the service had a visual deficiency that was previously unknown to school or parents. By recognising or identifying the cause of poor sight for the first time in a number of children, particularly those with no previous history of eye care, the service helps ensure children are on the right pathway of care.

For example, around a third of children need spectacles in special schools, yet not all are accessing spectacles or had the right prescription.

Around 6% of pupils have an eye problem that needs referral onwards for GP or hospital treatment. These can be serious, potentially blinding conditions if not identified, such as keratoconus or cataract.

The three teenagers we identified with keratoconus last year exemplify the need for ongoing monitoring of a child's sight using the right tools. Keratoconus is a condition which is relatively rare in the general population, but with a significantly higher incidence in the population of people with learning disabilities and often develops in teenage years. For all three children no subjective reporting of visual deterioration was noted so they were very unlikely to have self presented.

In addition all three cases were diagnosed by using retinoscopy - a technique used to assess the ability of the eye surface to focus light (this is also used to prescribe glasses). Retinoscopy has been found to be extremely important and the best way of picking up keratoconus in its earliest stages, but is a technique that is falling out of favour in mainstream optometry. Alternative tools being used have been found to be less likely to pick up the condition early on.¹⁵

This is important for people with learning disabilities as if keratoconus is picked up early enough a much safer and less traumatic technique called collagen cross-linking can halt its progress, otherwise if identified in later stages a corneal transplant may be needed.

Olu's story

Olu (not his real name) has global developmental delay. He was seen two or three times from around the age of 5 or 6 in the hospital eye clinic for routine checks. No concerns were mentioned at that time and glasses were not needed.

After missing an appointment at the hospital, Olu had no further eye care until a SeeAbility test at age 13 in his special school. Olu is quite an anxious teenager and would have struggled in a community optical practice.

¹⁵ Please see more about current research at this featured blog by the Down's Syndrome Vision Research Unit, Cardiff University <https://www.downs-syndrome.org.uk/download-package/keratoconus-and-downs-syndrome/>

At his test, Olu appeared to have a reasonably good level of functional vision and good control of his eye movements. But using retinoscopy we observed that Olu has keratoconus. We hope we have caught Olu's keratoconus in time for less invasive treatment options - he is currently waiting to see an ophthalmologist.

Not all ocular disorders do need referral – about half of these cases could be managed in school because the service benefits from the input of an orthoptist, again highlighting the benefit of a multidisciplinary model and mechanisms that allow for co-ordination with local hospital services.

Even issues such as squint and refractive error can have a significant impact on a child's education and development, their social skills and behaviour, if allowed to go untreated. At worst untreated refractive error and squint can leave a child with permanent sight loss if their eyesight is not supported to develop properly – with long term costs to the NHS and social care.

Abigail's story

8 year old Abigail has an autistic spectrum disorder and epilepsy. Abigail had her first ever sight test when SeeAbility visited her special school. The optometrist discovered Abigail is much more longsighted in her left eye than her right eye, meaning she could only really see with her right eye. If there is unequal focus between two eyes, it leads to the weaker eye not developing correctly (amblyopia). This can be easily corrected with glasses at a young age, but if left undetected and untreated can lead to permanent sight loss. Abigail has now got the glasses she needs.

Mum Michelle believes there's a real chance Abigail's eye problem would not have been identified early enough without the SeeAbility sight testing programme in special schools.

"I had never noticed any problems with her eyes, so the idea of a sight test had just never come up. Because of Abigail's behavioural and communication problems I wouldn't even have considered taking her to a local optician; it just would have been a nightmare. When it comes to doctor's appointments she doesn't even want to stay in the room, so unless we'd had a real reason to be worried about her sight I don't think she would have had an eye test. It's really frightening to realise her condition could be so serious later in life if it wasn't spotted and treated now. Knowing she could have lost her sight over something that is so easily corrected with glasses is shocking.

"I'm amazed at how well she's getting on with her glasses. She wakes up in the morning and asks for them straight away. This tells me she must be feeling the benefit, they must be making a real difference to her. It is particularly important for children like Abigail to feel happy and safe in a new situation, so it helped massively that she was in an environment she feels comfortable in and that the people involved could take the time to make it a good experience for her."

There is a high need for spectacle support

We are also able to highlight the benefit of spectacle support in school. Our observations were that there were many children who should be wearing spectacles, and even where they have been previously prescribed in the community or hospital eye services, they are not wearing them as much as they should be.

A large part of the dispensing work undertaken with a child with learning disabilities and additional needs is to take account of special facial characteristics, head posture, hearing aids and head rests for wheelchairs, while finding spectacles that offer both comfort and sturdiness against breakages as a child gets used to wearing their new prescriptions.

So while 31% of children need spectacles, this is not just a case of straightforward dispensing and the statistic does not reflect the 'true' level of interactions with the dispensing optician or level of need. In fact in the model it can be said that the dispensing optician probably sees the pupils more than the optometrist, because of all the necessary follow up work to support a child with spectacles.

Children for whom spectacles are part of their treatment for squint and/or amblyopia are monitored closely by the dispensing optician to ensure successful compliance. Fragmentation of care in other models - for example where spectacles are prescribed in a hospital clinic but dispensed in a community opticians make this harder to implement and would result in more missed school time for appointments.

Instead children receive their spectacles without disturbing the school day and often in a relevant educational context (i.e. it is actually very useful to have spectacles fitted while you are studying) as well as enabling SeeAbility to share the information with teachers and support staff about when to wear spectacles at school.

Making spectacles easy to access for parents/carers also continues to be a theme of the service. All parents in 8 of the 9 schools where we provided our service asked to have spectacles dispensed in the school setting. Only in the Trinity pilot did some parents ask to have their child's spectacles dispensed at a community optical practice.

As 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 special educational needs. Given some children are non-verbal, or may rely on their eyes to communicate (e.g. using eye gaze technology), being without spectacles is also going to have a significant impact.

The other value of the model is the ability to repair and replace spectacles quickly, so a child is not without their spectacles for very long – unlike if they were waiting for appointments in the community or hospital eye service. Again repairs and fixes to spectacles are very common, which is why finding the most comfortable and less breakable frames is so important.

Ben's story

Ben uses a wheelchair and head rest on the left hand side which means his head is in a fixed position resting on the left side. It was felt that the hard frame on the left side of the glasses would have been uncomfortable on the side of his head so was replaced with a soft strap to fasten onto the frame on the right side. These were custom made for Ben with careful consideration to ensure maximum comfort and correction of vision. Ben's parents were thrilled and said:

"When we were told Ben was visually impaired at 6 months old we never thought he would qualify for glasses as we just assumed Ben couldn't really see things or items. When we got Ben's diagnosis his health was poor, so an eye test was the least of our worries. But having the recent eye test and providing Ben with modified glasses has had a massive impact for him and the family, as we are enjoying bedtime stories with Ben viewing the pictures more easily whatever he sees. A big thank you to the team for the patience, time and giving our son a chance."



How Ben's spectacles are made for comfort

The school environment is key

The calm, familiar setting in school, with trusted staff and peers around them, relieves stress and anxiety for these children and means they much more likely to comply with a sight test and get used to eye care as they become young adults.

School services bring greater flexibility to reschedule/ carry out different elements of the tests on different days/at different times without any need to take the child out of school. 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. They also got immediate feedback from the sight test so findings could be discussed.

Even if a child's vision problems are already known, sometimes clinical terminology is not well understood. The ability to explain in layman's terms what a hospital eye clinic or prescription for spectacles means can in some cases be the first time a parent has understood what their child can actually see. The other most reported impact was the change in behaviour seen in many of the children who we supplied with spectacles. Once a child could see better, they seemed happier, more engaged and less likely to exhibit frustration or challenging behaviour.

Working in a special school provides an opportunity to work with those with expertise around the education of children with visual impairment. Overall 36% of children were referred to a QTVI- this includes children referred on as requiring support with spectacle wear as well as those with visual impairment.

James Boylan, Headteacher, Heritage House

"For the first time all pupils have had access to the services of trained and highly skilled eye care professionals who have arranged for the eyesight of our complex school population to be tested. In the case of visual assessment there is no longer a specialist service provided by the NHS as there is in other health areas so this collaborative work with SeeAbility has been the only way our children and young people can access a service that most people take for granted.

As a result, for many of our pupils they have had the first assessment of their vision in their lives with some prescribed spectacles for the first time. There has been a positive impact on the workforce too as colleagues are now more aware of the visual needs of pupils and the challenges some of them may have been facing in relation to accessing learning. It is a pleasure to work with SeeAbility and to see the daily lives of many of our pupils and their families transformed."



Charlie, a pupil at Heritage House School

Improving the model and looking ahead

While SeeAbility considers the service model has worked very well, we still recognise there are areas where we continue to learn and improve. SeeAbility 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. We continue to expand our service and look forward to working in more schools in 2017. We are currently making plans to take the service to the North West at New Bridge School in Greater Manchester.

Last year we recognised that we needed to ensure there was a greater uptake of the service, as we have to seek individual consent, each year for each child. We have worked to improve uptake and consent and our average of 70% is a great improvement on last year. We are amending our consent form to strive for a 100% response rate by asking parents to tell us where their child is receiving care if they do not wish to be seen in school.

We continue to refine our systems and now with the benefit of donated practice management software we are able to analyse our data in more detail. 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.

We continue to develop relationships with all the professionals involved in education and support for a child in a special school. As the service has progressed it has become very apparent that the support of QTVIs is essential in providing the best outcomes for pupils, and although input varies (some QTVI's are based in schools, some are based externally) we continue to build on this work.

Our project with Whole Child Therapy will help us produce information that we can share widely with QTVIs and other practitioners on how to support children with complex needs to get used to wearing spectacles. It is also clear the work is revealing how little clarity there is within the NHS voucher system for supporting children with special educational needs, who need comfort and fit, or substantial modifications to their frames. We will be taking up these issues with NHS England.

We also plan to publish a comparative study to demonstrate the difference in refractive error seen in a mainstream school population as compared to the special school population. As we approach testing 1000 pupils in 2017, our service evaluation will provide the richest global dataset on the eye care needs of children in special schools, which will bring more opportunities to highlight the benefit of a special schools eye care model nationally, and internationally.

There is no specialist qualification for eye care professionals working with children with learning disabilities. SeeAbility is now making plans to work with others to fill this gap. This needs to be addressed if a national special schools programme is to become a reality.

Conclusion

SeeAbility continues to call for a national programme of specialist sight tests in special schools in England, offering the 'right care, at the right time and in the right place', to a group at high risk of sight loss and sight problems. This is a group of children that are in real need of as much of a 'one stop shop' model of care as possible. Our work and that of others shows that a special schools service can work in practice.

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 this high risk group.

An unreformed system risks much higher costs being borne by health and social care if sight loss is not prevented. This is a growing group of children – for example there has been a 50% rise in children with complex needs and life limiting conditions since 2004¹⁶ and the number of children with learning disabilities and sight problems is also increasing.¹⁷

Eye care for these children is primarily delivered in hospitals, sometimes because it is clinically necessary, but sometimes because there is no community alternative. It is also clear that a more widely available vision screening programme at school entry is not the answer for children in special schools - 90% of the younger age group of children would fail the vision screen that is recommended at school entry, and could end up referred to secondary hospital care in many cases.

There is little capacity of hospital eye clinics to cope with increasing demand and referrals. There has been a 40% increase in outpatient attendances to hospital eye clinics in the last ten years, with 10 million of the 100 million outpatient appointments in 2013-14 taking place in eye clinics.¹⁸ Warnings have been issued about patients suffering delays to follow up care as well as a pressure to discharge patients without community eye care alternatives being available.

This scenario applies to children with learning disabilities as much as anyone but is even more pertinent as these are children more likely to struggle to comply with tests, or miss appointments. 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. The value of having a multidisciplinary team with orthoptic input and dispensing expertise allows these conditions to be treated as

¹⁶ Council for Disabled Children and The True Colours Trust (2017) Understanding the needs of children with complex or life limiting conditions <https://councilfordisabledchildren.org.uk/news-opinion/news/numbers-children-complex-needs-50-2004>

¹⁷ Emerson and Robertson, 2011, *The estimated prevalence of visual impairment among people with learning disabilities in the UK*

¹⁸ Please see Royal College of Ophthalmologists statement www.rcophth.ac.uk/2016/03/increasing-demand-on-hospital-eye-services-risks-patients-losing-vision/

part of a 'one stop shop' of support, and there is much more likelihood of spectacles, if supplied, being worn.

A new national programme would fit strategically with the aims of NHS England to prevent sight loss and address health inequalities in a vulnerable and high risk group, a group which national optometric and learning disability programmes have so far overlooked in terms of adequacy of optical funding and promotion of good eye care.

We continue to press the case with NHS England for a fully funded, special schools sight testing programme to be accepted and introduced at a national level. SeeAbility will also continue to press for the Welsh Assembly Government to progress its own proposals¹⁹ for a dedicated special schools sight testing service in Wales.

¹⁹ 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 practice²⁰, 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

Pupil numbers are published in government figures. Overall there are 109,150 pupils in special schools.²¹

However this does not include pupils in independent special schools or post-16 specialist colleges. In independent special schools there are at least 12,445 pupils.²² The Department of Education has confirmed to SeeAbility it does not collect the primary SEN needs of children in independent schools (e.g. autism, profound and multiple learning disabilities).

It is important to note that not all special schools cater for children with learning disabilities or autism.

²⁰ Department of Education and Department of Health. SEND Code of Practice: 0-25 years (2014) www.gov.uk/government/publications/send-code-of-practice-0-to-25

²¹ See here www.gov.uk/government/statistics/special-educational-needs-in-england-january-2016?platform=hootsuite extracted using the “underlying data table” on this page and filtering column ‘O’ by special school types, and then calculating overall pupil numbers from column ‘U’.

²² This is from SEN statistics team underlying data at the website above.