

Eye Care and Vision Strategy

2021-2023



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Executive Summary

SeeAbility are at a pivotal time in our mission to ensure a more equal right to sight for all people with learning disabilities and autism. The next 3 years will bring about opportunities to further build upon our significant successes in the eye care and vision sector and allow us to capitalise on our track record of success as a respected authority and trusted partner in influencing and delivering change. We recognise that this strategy is, necessarily, malleable in the face of COVID 19 and new overall strategy for SeeAbility. The aim for this strategy is to be adaptable to and enhance the work and reputation of SeeAbility overall.

Since the inception of our public health work there has been a carefully planned balance between the creation of new and more accessible services and the requirement to educate and raise awareness through our eye care messages. Both work streams have informed and supported our success in influencing national policy to date. Our previous strategy delivered on our aim to lay the foundations for improved national sight testing services for people with learning disabilities. This has been achieved with a commitment in the NHS England 10 year plan to provide comprehensive eye care services in all special schools and with the recruitment of people with lived experience of disability to specialise in educating people with learning disabilities and their supporters to be eye care aware.

This strategy will build on these achievements by ensuring planned services and government policy commitments become a reality. We will use targeted projects, research studies and new approaches, grow the team and extend our reach to more people and new audiences, with the outcome of greater inclusion for people with learning disabilities and autism, in line with our theory of change. Unapologetically, we are setting ourselves a high bar: an intrinsic role in the permanent transformation of national eye care provision for people with learning disability and autism.

- **Making the special schools programme a success**
- **Educating and reaching more people and new audiences**
- **Influencing for a more equal right to sight**

Introduction and Context

SeeAbility has been leading the way on improvements to, and the importance of, eye care for people with learning disabilities and autism since 2005. We have achieved our ambition of being the go to and only organisation on this subject. Our paced, adaptable, evidence based and person centred approach has led to our national reputation as an organisation who makes things happen and are consulted because of our knowledge, experience and passion. What we have to say hasn't changed over the years but the methods to communicate it and influence change have evolved. We have showcased and shared best practice in our ongoing mission to ensure people with learning disabilities are at the right place on their eye care journey, receiving equality of access to the right care at the right time and in the right place.

Key achievements during the previous strategy period 2018-2020:

- We have had a leading role in the NHSE stakeholder group set up to plan a national special schools eye care service. This group was set up in response to the pivotal 'Framework for Special Schools Eye Care' paper SeeAbility produced with the input of all the eye care professional bodies. We have led on the authoring of a service specification and competency framework that will underpin these new services. We have worked in close partnership with NHSE with fantastic support across the eye care and vision sector and with the voices of learning disability and autism and special educational needs representatives during these early planning stages and are now ideally placed to support the successful roll out of this national program to all special schools in England.
- We annually test 900 children (1,581 children to date in total) attending special schools and have dispensed 2,038 pairs of glasses while learning from the experiences of the children, parents and schools' staff.
- We have published the findings from our service in peer reviewed academic literature with the committed support of Dr Maggie Woodhouse, Cardiff School of Optometry and Vision Science. Our work is currently the largest global study investigating the eye care of children in special schools.

- We have published numerous articles in the peer reviewed and grey literature and delivered lectures, seminars and workshops at most major eye care and learning disability conferences and events, significantly building awareness of SeeAbility within the policy and clinical eye care and learning disability arenas as well as with key academics in the field.
- Our special schools work received 3 national awards, the NASEN (National Association of Special Educational Needs) Provision of the Year award, the Dispensing Optician of the Year award and a College of Optometrists Research Excellence award.
- We secured multiyear external funding to recruit and train a team of 7 eye care champions with lived and work experience of disability covering the London and the North West regions, so far making 3,715 people more eye care aware and learning disability friendly.
- The refreshed Local Optical Committee Support Unit Learning Disability eye care pathway includes our recommendation of commissioning and funding experts by experience/self-advocacy groups to support the promotion of the service when commissioned by CCGs in future as engagement leads. Alongside support from our Eye Care Champions to advise on how best to promote the service.
- In anticipation of national policy changes, we have developed our information resources ready to support the process at all levels. We have created and disseminated guides, added to our web based resources, contributed to webinars, and delivered workshops and training to audiences involving key stakeholders in the process. Since 2018 our web based information service has had 18,942 downloads of resources and we have responded to 273 enquiries.
- We have grown our social media reach to 592,806 including successfully engaging with 5,810 people through our regular eye care mailer in the past 18 months. We have established a clinical team Linked In page aimed at eye care professionals which has 160 members.
- We have stimulated the need for advancements in testing techniques and further clinical pathways for those who need glasses, surgery and support to live with sight loss.

Our Children in Focus campaign will be our long lasting legacy, achieving national change in the delivery of eye care to over 120,000 children attending special schools in England, getting it right for the next generation. During the previous strategy we paused our planned activity in some areas to target our energy and resources towards ensuring that the inequality in access to eye care for children with special educational needs was resolved. Our perseverance and investment has been rewarded by inclusion of a commitment in the NHS England Long term plan in 2019 to provide in school eye care services, the only eye care initiative mentioned in the whole document. Ownership of this commitment now lies with the NHS in terms of delivery but with SeeAbility acknowledged as a key partner in ensuring the success of this initiative going forward. There is a clear NHSE commitment that the special schools programme is just the start of the evolution of primary eye care services for people with learning disabilities and a project team has now been recruited for the implementation stage.

2020 has been an unprecedented year, with the country affected by a worldwide pandemic which has further highlighted the inequalities faced by those most vulnerable and disadvantaged in our society. These needs have been recognised by NHSE's CEO:

"Our commitments to people with learning disabilities and/or autism remain central to the NHS's agenda. Colleagues have been very supportive of this, recognising that our commitments and responsibilities in these areas are crucial to helping people with a learning disability, autism or both lead longer, happier and healthier lives."

There is a significant opportunity for SeeAbility to be instrumental in helping government address this agenda, including in supporting the development and delivery of the government's promised national Oliver McGowan mandatory training in learning disabilities and autism which is to be delivered by people with lived experience to all health and social care staff.

The continued promotion of GP annual health checks for people with learning disabilities creates a mechanism to address unmet health needs. We need to ensure eye care, which has been proven to impact on life expectancy and quality of life, is not overlooked and included in the planned exemplar sites. Finally, the exposure of people living unnecessarily

in Assessment and Treatment Units (ATUs) highlights the need to address behaviours that challenge through positive behaviour support and identifying and addressing unmet needs, including those related to eyes and vision, rather than restraint and sanctions.

The provision of community and hospital eye care throughout the pandemic has had to rapidly adapt to meet need and demand within the changing restrictions. This has led to opportunities to deliver services more efficiently but also raising concern around equity of access for patients with learning disabilities. This is alongside a plethora of reviews and consultations in a sector urgently in need of reform where we have contributed the voice of people with learning disabilities at every available opportunity. This comes at a time when the visual impairment and eye care sector itself has lost the facilitation of Vision UK in bringing people together, including those with a special interest in learning disability and autism, making it all the more important we are well networked and able to fill these gaps.

The next three years will see us move to a new phase in the critical work we have started with NHSE and the eye care sector, that of the widespread implementation of services we have long campaigned for. These ongoing partnerships at a national level will further increase our presence and voice within the learning disability sector. This new strategy has been produced from engagement with the whole eye care and vision team, trustees, colleagues from other internal departments and external stakeholders including NHSE. We are now in a strong position to leverage the credibility we have gained to date to continue to provide leadership, innovation and direction to continue to make inclusion a reality by ensuring people with learning disabilities and autism can see as well as possible and in doing so lead flourishing lives. We should be showcasing ourselves as an exemplar organisation, we are recruiting people with learning disabilities, autism and sight loss as colleagues in delivery, adapting our recruitment practices and helping ensure we are a 'Disability Confident' employer. Operationally, we have a wonderful opportunity with our eye care clinicians, our eye care champions and our vision rehab specialists to really embed eye care awareness as a social care provider amongst our 600 support workers, who will go on to have that awareness and share it with others throughout their future careers.

The new strategy will centre on the following three work streams underpinned by targeted research and sharing best practice in all areas with creative and accessible communications:

- **Making the special schools programme a success**
- **Educating and reaching more people and new audiences**
- **Influencing for a more equal right to sight**

Strategic Activities

The mission is to ensure that all people with learning disabilities and autism are at the right place on their eye care journey through awareness, education and access to appropriate services. The premise of meeting basic health care needs first, such as good eye sight, is fundamental to enabling people to explore their hopes, dreams and aspirations for how to live their life in the future. This applies to all of society. Opportunities to include eye care as a priority to improve the overall health and wellbeing of people with learning disabilities and autism will be constantly sought. Our philosophy will change to move away from plugging a gap and charitably funding the work to put the responsibility and ownership onto where it should lie with a sustainable role for us to be part of the solutions in future.

The following three work streams are planned for the next three years:



Ensuring the special schools programme is a success

After 7 years of investment from the charity, the special schools programme is now at a critical point with SeeAbility seen as a key partner in the short and long term future. We have significant leading roles within the programme alongside the new NHSE project team. Our current special schools leaders are committed to showing new schools the difference the service has made and are welcoming for new clinicians to learn from them.

The **Special Schools Team** will dedicate their time to supporting this programme and creating a sustainable long term role for the charity in this area.

Specifically:

- We will increase our sight testing in schools to up to double the current case load to 1,800 children by applying for new contracts in the new national framework.
- We will support the work force development that the national programme needs through the provision of training services including a face to face and/or virtual mentoring programme for clinicians in new services during the proof of concept period and the development of a long term training and accreditation programme as imminently agreed funded work with the College of Optometrists and NHSE.
- We will look to create options for future operating models for our sight testing programme including structures, growth, contracts, procurement, processes and premises. This will allow SeeAility to pass on our training and expertise to practitioners across the country and lead by example.
- We will ensure all special schools in England are aware of SeeAbility and the work we do through the planned distribution of the NHSE commissioned families guide we have produced about eye care, as well as direct input into the establishment of new sight testing services through consultancy and training.
- We will seek funding for and have an instrumental role in establishing the data collection system for the new special school's programme. The aim will be to ensure data can be evaluated and reported upon for audit and research purposes and that data collection can integrate with the wider NHS data systems, a current priority for NHS learning disability services. We will ensure that systems can also effectively capture case studies to articulate the impact for children and families.
- Our specialist clinicians will have a platform to publicise this work and their knowledge, enhancing our credibility in this field, and supporting the case for sight testing programmes in other areas of the UK and globally.



Educating and reaching more people and new audiences

After 15 years of public health work the eye care messages remain the same, to empower people with learning disabilities and autism to access the eye care they need, alongside educating those who support people on why eye care is important and how to navigate the system. The Every Day in Focus programme is going from strength to strength so the eye care and vision team will continue to explore, pilot, evidence and deliver creative ways of making people eye care aware by targeting new audiences and using innovative methods (including digital) to reach more people. We will continue to do this in partnership and through others with the aim to expand the programme to cover two more regions, if funding opportunities arise, to show the impact that addressing unmet eye care needs has on people.

Specifically:

Reach

- Through our funded Every Day in Focus Programme **10,000 people will be reached** directly with our eye care/learning disability messages through a blended approach of face to face and virtual delivery across London and the North West and through others e.g. emerging self-advocacy support networks, radio stations run by people with learning disabilities. These regions will be a test bed for new and innovative ways to make people eye care aware or learning disability friendly in collaboration with statutory, private and voluntary sector partners, with attention to evaluation to be able to share learnings and contribute to best practice in the learning disability sector.

- Through commissioned work **500 eye care professionals** will receive virtual and face to face General Optical Council accredited continuing education training /continuing professional development about the needs of patients with learning disabilities, always involving co-delivery by clinicians and people with lived experience from within the team. This will lead to a better understanding of the need for commissioning more learning disability pathways, learning disability champions embedded in local optical committees, removal of assumptions and improved confidence in communicating with people with learning disabilities in practice. This training will also lead to increased use and understanding of the reasonable adjustments that improve the experience and outcomes of eye care for all involved.

Growth & Innovation

- Dependent on the renewal or desire for expansion of our current funders we will aim to **grow the Every Day in Focus programme** to recruit eye care champions and mentors to work in two additional regions with priority being the South East and South West areas where our social care provision growth is also planned.
- Recognising the need for **digital solutions** and the future proofing of our work, with Marketing and Communications, we will **scope out the need, purpose and cost of an information advice line**, web chat service and closed social media groups/forums to support and compliment the web based information service.
- The structure for a **SeeAbility run national network of learning disability engagement leads** will be scoped based on the successes of the eye care champions increasing uptake of the LOCSU learning disability pathways in their regions.
- We will explore an external **research partner** to evidence the effectiveness and impact of the peer to peer methodology in eye care awareness raising. This will provide the case for the expansion and continuation of the Every Day in Focus programme and the evidence base for the recruitment of learning disability engagement leads in newly commissioned learning disability eye care pathways.
- We will scope, design, cost and check we have capacity to deliver an **eye surgery support and advocacy service** based on our

experiences so far to be commissioned as expert advisors in the best interest decision making processes. This will form the evidence base for future campaigns to reduce the currently only anecdotal inequality of access to treatments and surgery to then empower patients, families and supporters to speak up about inequality and challenge discrimination.

Information & resources

- We will continue to lead on including **specialist information** about sight testing and functional visual assessment for new audiences within the **positive behaviour support community and portage services for pre-school children**. We will utilise in house knowledge and connections to establish these links and deliver through contributions to existing forums, webinars and circulation of our resources. We will aim to upskill eye care and vision champions in these networks who can impart their knowledge to others.
- We will establish an internal working group with operations to learn from and condense our internal Eye Care and Vision Charter to create, pilot and evaluate, in our Every Day in Focus areas with other providers, a succinct and accessible set of '**Eye Promises**.' This will be for any learning disability and autism social care provider to simply sign up to and implement, leading to more people accessing eye care and reporting increased inclusion from improved vision and understood visual abilities. They will also have a menu of additional services they can obtain/purchase from us e.g. use of easy read materials and eye care aware resources, staff training and peer to peer education for the people they support. We will utilise any existing internal relationships to gain support for the initiative at inception from regulators and statutory services such as CQC, ASASS, NHSE, safeguarding networks to give providers an incentive to sign up to it and see the benefit of doing so.

With NHSE funding, we will co-produce **children and young people friendly information and resources** to prepare to access eye care and to improve the effectiveness of clinical assessments. These will also give parents peace of mind and information to use to compliment the parent's guides which we have already been commissioned to produce.

Networks, collaboration and best practice

- Working in collaboration with the Optometry Schools Council all schools of optometry and dispensing optics in England will be provided with a **kit and educational offering** so that all undergraduates are consistently taught by people with lived experience about the needs of people with learning disabilities. Funding and endorsements will be sought from existing or new partners to deliver this piece of work.
- We will work with NHSE and key stakeholders and obtain funding to create an **eye care public health communications plan for the learning disability and eye care sector**, including the creation of new resources such as an accessible animated film of the eye care journey to be used by any provider and shared through all media channels.
- Eye care champions will **connect with** the organisations awarded the contracts, such as **Pathways in the North West**, to deliver The Oliver McGowan Mandatory Training in Learning Disability and Autism for health and social care staff to provide insight as to how to reach the optical sector and identify what their learning needs are from our experiences.
- Eye care champions will ensure **good practice and pathways in eye care** is included in a least two of the areas identified as 'Annual Health Check Exemplar sites' in London and the North West to then share nationally.
- We will continue to **publicise and grow our face to face and virtual eye care and learning disability training offering** for all our audiences through our direct work, social media activity and networks. On an individual basis and dependent on the location we will decide if our training is free of charge, paid for or part of a skills and knowledge exchange.



Influencing policy for an equal right to sight

The ambition to create an equal right to sight is by no means fully accomplished with many more battles ahead, but we have greater understanding, increased authority and a proven track record to tackle the remaining inequalities that exist along the eye care journey. The pace, successes and challenges in the above two work streams will dictate the timing and inform the need to research, lobby and campaign further. **The Equal Right to Sight** campaign will focus on influencing policy to address the following three priority areas:

- Ensuring successful uptake of eye care interventions, including the successful use of glasses, access to eye surgery and timely rehabilitation and habilitation support in collaboration with internal and external stakeholders.
- Highlighting and evidencing the link between behaviour and poor vision through research and fact finding, with particular focus to how this impacts on and can be included in the Transforming Care agenda.
- Bringing together experts to improve the consistency in management of cerebral visual impairment (CVI) as well as opportunistically building on and advancing research from our ongoing clinical activity in our schools and support services.

Specifically:

- We will establish, recruit to and have oversight of a virtual **learning disability and autism eye care special interest group**, bringing stakeholder organisations together with a clear purpose and achievable objectives, in response to the loss of Vision UK and its learning disability eye care sub-committee. This collaborative group would meet a need to discuss policy issues and collaborative working.

- Our eye care champions, learning disability engagement leads nationally and a growing bank of case studies will be at the **heart of influencing what needs to change** to embed eye care into learning disability policy and learning disability into eye care policy so no one has their needs left unmet and the voice of people with lived experience is heard.
- We will continue to work with NHSE to develop and if needed lobby for a new **national framework for specialist community primary eye care services** for people with learning disabilities to access and be referred to from their GP annual health check, the special schools service and hospital eye care services in the long term. We will also make sure the needs of people with learning disabilities is addressed in the evolution of generic primary eye care services so no one is left out.
- In the short term we will also continue to **work with LOCSU** (the national Local Optical Committee Support Unit which develops service pathway frameworks for local NHS commissioning) to support local providers in establishing locally commissioned services (commissioned by CCGs/ICSs) with involvement from self-advocacy groups and/or recruitment of experts by experience as learning disability engagement leads.
- We will scope out a study in an **assessment and treatment unit** (ATU) to explore eye care history, visual status, barriers to testing and staff eye care knowledge involving multidisciplinary collaboration between an external Positive Behaviour Support (PBS) consultant and an Optometrist. The study is intended to provide evidence of links between behaviours that challenge and poor vision. Identifying and where possible rectifying undiagnosed sight problems at the earliest opportunity has the potential to transform lives and open up future opportunities for thousands of people currently living in ATUs.
- We will endeavour to ensure **new education and training standards** for the whole optical sector education reflect the needs of those with learning disabilities.
- We will work with the **eye care sector to bring experts in the area of CVI together** through round table discussions and events to agree pathways and map and disseminate regional areas of specialism to link to the special schools programme and community pathways. We will continue to analyse our findings in relation to CVI from our clinical activity as a basis for any further research.

- In collaboration with the optical bodies we will **evidence the need for specialist dispensing and glasses adherence support and interventions** for children and adults, filling a gap in knowledge and leading to the creation of a user friendly, person centred, glasses support plan for any supporter or clinician to use. This will be used to advance the case for policy change to ensure glasses dispensing is provided for people with a learning disability by a regulated eye care professional.
- The **Bradford Visual Function box** will be available for purchase and distribution to new special schools services and beyond. We will continue to engage and influence partners in developing additional and innovative ways of testing for people with learning disabilities and autism.

Conclusion

This plan supports SeeAbility in achieving its five year strategic aims, particularly in regards to our aim to increase our influencing, social impact and partnerships work. Specifically, this provides us with the opportunity to realise the aim set out in our five year strategy of 'we ensure that everyone with a learning disability, and those that work with them and support them, are aware of the prevalence of sight problems, associated concerns, their rights and are able to access practical support'.

All of the work included in the strategy is designed to build on the work already undertaken to meet the goal of:

Enabling and empowering people with learning disabilities to be at the right place on their eye care journey, leading to increased opportunity and a more inclusive society.

The next three years are crucial and will see many of the past 15 years of public health work, campaigning and learning come to fruition. It enables the charity to be a national voice advocating for equality and inclusion for people with learning disabilities and autism which is mirrored in and supports all the other work of SeeAbility.

Appendix

The Eye Care Journey

Be eye care aware

SEE **ABILITY**

These are the essential things to think about when supporting people with learning disabilities.



Think vision

People with learning disabilities are much more likely to have sight problems. But many are not getting the eye care they need.



Have a sight test at least every 2 years

You often can't tell if someone has a sight problem. The only way to know for sure is a regular sight test.



Wear the right glasses – and look after them

6 in 10 people with learning disabilities need to wear glasses. People need the right glasses for the right task and support to get used to wearing them. Glasses should be kept clean and well maintained.

Get the right support

The right support to manage eye conditions and live with sight loss is essential. This could include:

- Access to treatments and eye surgery
- Support to make the best use of someone's vision
- Specialist equipment and support for people living with sight loss

More eye care information at SeeAbility.org
Available to download and use as a poster.