SeeAbility response to the Special Schools Eye Care Service proposals

Summary response

We welcome this engagement opportunity to share our thoughts and experience of providing eye care in special schools since 2013, and under the NHS contract since 2021. We congratulate NHS England on the achievements so far: the independent evaluation of the proof of concept service evidenced it to be successful in delivering high quality and safe eye care for thousands of children in exceptional need, with a service now in around 8% of special schools.

The service reflects the pathway of specialist support and the ongoing surveillance that these children need, with sustained glasses wear being key in good outcomes for these patients, both in maximising functional vision and because uncorrected refractive error leads to poorer visual outcomes in later life.

The changes now proposed to the service are more substantial than recommended by the evaluation and could undermine those positive outcomes. It would introduce a new experimental phase in the rollout, where removing mandated requirements on training, dispensing and equipment could lead to more inconsistent, poorer quality and incomplete care. This could lead to significant unnecessary referrals into secondary care.

We seek assurance that other elements of the proof of concept model not referenced in the engagement proposals, such as named clinicians being contractually obliged to provide quality of care and limiting the number of claims for children seen in a school day to 8, will not be changed.

The clinical and additional needs of these children are not emphasised enough in the engagement documents: these children are in special schools because they are identified as needing significant additional support, for example teaching staff ratios are much lower, there are other clinical and specialist teams in school, and their needs cannot be compared to neurotypical children.

We also understand NHS England must consider making this service straightforward to commission and ask for regard of the following:

 To meet the departmental commitments to a national service and consistent offer aimed for in SEND reforms, we urge NHS England to produce a national specification and commissioning guidelines with a nationally negotiated fee (GOS amended additional services contract).

- As ICS's will commission the service, some clearer commitments on how the service will be funded, quality assured and audited are needed. The current model is already supported by a specification, professional guidance and KPIs and a dedicated platform to collect data. These can be reviewed, enhanced and be part of ongoing evaluation as the service is implemented.
- 3. Free of charge glasses, spares and repairs, the input of dispensing opticians and the specialist frames and lenses children need are all at risk under changes away from the original 'not for profit' model of spectacle provision. The evaluation evidences these elements of the model to be vital in ensuring optimal visual and educational outcomes. To maintain the quality of dispensing for this most vulnerable and complex paediatric population we feel the inclusion of the dispensing optician in the model is crucial.
- 4. Maintain the elements of the service that worked well and provide the safeguards necessary and expected of any other specialist service for vulnerable patient groups, such as a list of required equipment and a practical training programme, so ensuring those providing care are equipped and competent to do so and this is recognised in the fee for care.
- 5. Parental engagement and school support is key, and the emphasis on the written report is very welcome, but reducing barriers in accessing glasses is fundamental to the service so children get equity of sight correction. A solution that mitigates against financial co-payment by parents is needed, along with appropriate funding, promotion and engagement as part of the overall scheme, to ensure it is meaningful, viable and impactful.
- 6. More rigorous analysis and publication of clinical data collected from the proof of concept service, and additional fieldwork, would help drive understanding of the level of need in special schools and the potential of this service to get 'complete' care to these children. This should include analysis of numbers of children who have been discharged out of hospital care to the service and be complemented by the creation of an implementation advisory group representing clinicians, schools and parents.

The service has potential to transform lives and meet many NHS goals to prevent health inequality, support children with SEND and reduce ongoing pressures in outpatient care. The special schools service should be a platform for further eye care reform for all people with a learning disability given the very high risk of sight problems.

Full response

The evaluation demonstrates the NHS service meeting huge unmet need with 51% of children not having a history of a previous sight test, and working exceptionally well from clinician, school, and parent feedback (albeit the evaluation only reached 115 parents of whom only 82% had used the service). The positive feedback aligns with our recent satisfaction survey where over 400 parents (19%) responded.

NHS England should be congratulated on the achievements of the programme - so many children received the eye care service and glasses that fitted them properly for the first time and they were supported to sustain wearing them. 75% of schools saw 'significant' outcomes for their pupils, some 4% of children referred on for treatment of more serious sight issues and no school being unhappy with the service.

With the proof of concept providing such excellent results and the evaluation confirming that the model of care works well, we encourage NHS England to adhere closely to the proof of concept model, which clearly delivered optimal outcomes for children, and is cost effective at minimising referrals into secondary care. As the evaluation states: "only nominal adjustments would need to be made to support a permanent rollout" and "coupled with the role of children's families the service is an excellent example of true integrated working, that has the potential in the short term to reduce demand on specialist secondary care services and more importantly, improve outcomes for children living with a disability."

Key points for consideration.

History of programme and case for changing a successful model of care

The evaluated service rolled out to 83 schools was based on work undertaken by NHS England from 2018 -2021 with the benefit of an external expert advisory group. This in turn was based on many years of development and history of programmes working in special schools, including SeeAbility's Department of Health funded innovation programme and the development of a <u>Framework for special schools eye care</u> recommended by Public Health England. There is a large amount of work behind this existing programme.¹

¹ The documents and arrangements developed included the Clinical Framework for special schools eye care, endorsed by Public Health England and then NHS England (2018), A Service Specification (2019), and Core competencies framework (2019). The use of an amended GOS 'additional services' contract (used by both primary and secondary care providers) (2021). Specific training and shadowing arrangements for clinical teams (2021) accredited by City, University of London. A trial fee set by NHS England and arrangements for glasses dispensing that did not involve 'cross subsidisation' of clinical care through reliance on the NHS glasses voucher

It was understood that the proof of concept was to help NHS England understand if the 'test' fee was appropriate to deliver the service and the collection of 24 data fields through the BSA platform would allow for clinical and economic benefits to be explored. Through this we would begin to really understand the level of need in special schools and potential of this service to get 'complete' care to these children.

The evaluation states that economic analysis and assessment is "*being completed separately*". A publication of this economic analysis would be helpful along with fuller data from the BSA platform, to ensure NHS England proposals are justifiable, proportionate and best value. Such data could inform:

- ability to discharge children out of hospital care based on hospital history.
- the value of a not-for-profit model of glasses dispensing.
- levels of and magnitude of refractive error, eye disease, suspected cerebral visual disorders and overall visual impairment.

Without the fuller data and cost picture, there are some risks around quality of care and cost effectiveness emerging from the proposals.

Need for a national service specification and national (sustainable) fee

We call for a for the service to be fairly commissioned using a nationally negotiated additional service GOS contract with a clear service specification and nationally negotiated fee (in parity with the proof of concept period).

The specialist nature of this scheme, delivering equality of access and a less fragmented pathway of eye care, and the consistency of support being championed by SEND reforms, justifies a national approach to setting out expectations, standards and funding. This can then be commissioned locally by the ICSs with contracts awarded to the most competent providers, some of whom will already be delivering the service with proven success and have become familiar faces in their local schools.

The Secretary of State and NHS England have the legislative powers to specify for Primary Ophthalmic Services through the GOS contract. Doing so for this service would provide long term certainty for the programme and meet the national promise of it being made available to 165,000 children in NHS England.

scheme (2021). An equipment grant provide by NHS England to part fund specialist equipment needed by providers (2021). Handbook for schools (2021).

It is unclear how ICS's will be supported, but tendering may imply variations in quality, consistency or financial viability to deliver the service, which could mean gaps in services. It is so important that ICS's support the rollout so that providers and schools have the confidence to come forward. We know of many different contractors that have come forward and expressed interest in providing the service, including hospital trusts and universities, as part of a mixed economy of care. As the evaluation states: "A strong commissioning framework based on need should provide a robust vehicle for practitioners to support delivery and achieve the desired outcomes for children and their families."

We appreciate that it is not within NHS England's gift to 'mandate' special schools to host this service. However, we do know there is a huge appetite amongst schools for this support. We would welcome understanding how school networks nationally and regionally will be engaged and schools supported to host the scheme.

Need to build in quality assurance/oversight/audit

While it is appreciated NHS England is no longer commissioner for GOS services there will be a need to ensure quality given the vulnerability of this patient group, and that data collected is subject to ongoing audit and evaluation. We support the use of a national service specification with KPIs – as in the 'original' specification and guidance document,² helping to set expectations and mitigate risk.

Continuity of staff teams, to allow for children to build a rapport and trust with familiar professionals is vital and should be a contractual obligation as in the proof of concept. Guidance for schools is needed to enable understanding what a good eye care service looks like should continue, and what to do if they are concerned about performance issues. School handbooks to this end have been developed by the NHS programme team and are used by the proof of concept providers.

It is absolutely crucial that there is good engagement with secondary care services and referral criteria. For some children there will be a need for shared care arrangements that can help mitigate against duplication, particularly through the support of orthoptic services.

We also urge NHS England to evaluate further if the untested changes go ahead and to have a mechanism to engage with and seek advice from clinicians, professional bodies, special school and parent bodies as the new scheme rolls out.

² These included KPIs such as recording of refractive outcome in >90% cases, referrals and reports sent within 5 working days, referrals into secondary care between 5-10% dependent on local protocols, proportion of spectacles dispensed within voucher value being 95% and also set expectations on timescale for spectacle provision and visits to replace damaged spectacles.

Need for specialist dispensing given crucial role in outcomes

Without glasses 42% of special school children cannot see properly (compared to 2-5% of the overall childhood population at age 5): and for many of these children they lose their prime way of communicating with the world around them. Sustaining glasses wear is helping their vision develop correctly. So dispensing is the most crucial 'sight saving' and 'life changing' part of the service.

Equity of care requires a much more proactive approach than for the neurotypical childhood population who can much more easily communicate their needs and what they can see. Of all children (who in any case by law under the Opticians Act should be seen by a regulated professional for their dispense) the special school children are most in need of regulated care.

Good quality dispensing, including routine follow up and free glasses maximises successful vision correction and development. In the evaluated model the dispensing optician is visiting schools or classrooms alone and does not need to be supervised to ensure that children have been routinely followed up with their new glasses (6-8 weeks) and have the glasses, fitting, adaptations and repairs on site they need. This provides value by ensuring maximum visual correction and less wasted appointments and does not need to involve the optometric time.

Moving the model to one where glasses vouchers are in use introduces new barriers for parents and schools (see below) but also risks the loss of specialist dispensing support unless this input is recognised in the fee for the service.

We suggest the service specification is clear on the need for a dispensing optician and their input is recognised in the fee for the service (not maximised margins on vouchers to 'fund' their time, which may risk perverse outcomes).

Need for good quality glasses and frames to achieve outcomes

The proof of concept model sought to address the risk of children getting poor quality glasses and poor fitting frames which leads to breakages or children not wearing their glasses. NHS England contracted directly with a spectacle laboratory to provide complete spectacles (frames and lenses). The dispensing opticians could order from a fitting set of 60 frames not ordinarily available in the high street and chosen to provide a wide range of quality and specialist adjustable and robust models. These were ordered based on clinical judgement and NHS England was invoiced independently by the laboratory so that the providers had no financial incentives.

We recommend that a minimum set of frames should be recommended as part of professional guidance, regularly updated to accompany the commissioning framework. This is particularly important if children are to lose access to an automatic spare pair, the quality of the 'first' pair dispense is crucial.

Need for equity in sight correction, not equality with the high street offer

There is a need for parents to be supported financially to cover most bespoke solutions these children need. This would avoid the risk of parents cross funding the new national scheme to achieve equity in sight correction for their children.

Moving from a free of charge model that was well received, to one of additional cost only creates additional barriers in children getting the glasses they need, undermining the most important outcomes of the service. It creates logistical issues for providers and for schools, with money changing hands in ways they would not expect from any other NHS service on their property.

As stated in the evaluation, it is extremely hard for these parents and carers to access high quality, lightweight and comfortable frames that are affordable, their children often need significant prescriptions resulting in thicker heavier lenses, if lighter = thinner solutions, these are an additional expense. The value of the service is the ability for dispensing specialists to offer bespoke solutions, upgrades to lenses and frames that mean children wear their glasses for longer, sustain glasses treatment - all without the barrier of cost.

The spare pair system was there to ensure children were not without their glasses for long if the first pair was broken. Children with developmental delay often need significant additional support to successfully adapt to wearing glasses, so if these are broken or lost, then that momentum is lost.

It is unclear from the survey what is problematical with 41% of parents receiving a spare pair – if this is of parents responding then that correlates with the % children with refractive error who need glasses.

The description of parents wishing to have the choice of going to the high street with a GOS glasses voucher or accessing a wider range of frames is not one we recognise from our 10 years of delivering a service. We never received a parental request for a voucher during the proof of concept. And in the evaluation it was concluded that "the desirability of a voucher is not imperative to the success of the service".

We would urge NHS England to explore ways to financially support not just parents in special schools but parents of children with learning disabilities in accessing glasses in the community more easily, by improving the 'GOS' offer and choice available, including the process of accessing second pairs. This would help drive more equitable outcomes rather than restricting everyone to the standard scheme.

Need for experiential training

The proposals to change the requirement to complete a specialist practical training programme, with mentoring and shadowing in schools, is a huge concern in terms of quality and specialism of the service. It will be concerning for parents and schools.

It is also a disinvestment in a valued training programme which NHS England had set up already, tailored to delivering the service in a different setting and to a separate set of requirements than professional core competencies. This includes how to facilitate, assess and dispense a child in a special school environment, integrate your work with school teams and tailor a report and recommendations which ensures parents, school and the other professionals involved in the child's education, health and care all understand what a child's visual abilities, needs and limitations are.

We could find nowhere in the evaluation that providers found the NHS England funded training onerous or restrictive (as is stated in the engagement document), and the evaluation states the 'familiarisation days were highly regarded by schools'.

Visits to special schools and professional shadowing and mentoring is not something the (albeit very welcome) Oliver McGowan mandatory training (OMMT) in autism and learning disability delivers. Specific training for the special schools eye care service is justified. There are other specialist services dedicated to this vulnerable patient population where additional training according to that profession required, the most comparable being special care dentistry.

We would encourage NHS England to supplement the commissioning framework of the service with professional guidance on training, so commissioners can be assured that whoever they award contracts to has the required competencies to deliver benchmarked against the existing training programme requirements. It is also important that the fee in use recognises the need for this training, if NHS England no longer funds any training directly.

Equipment

While NHS England no longer intends to part fund additional equipment it is still possible to provide a recommended list of the equipment to be used for this specialist service. This can form part of professional guidance alongside the service specification.

Again, without this as a benchmark, the change raises risk of services being commissioned of variable quality, particularly if left to the discretion of the provider and inexperienced commissioners. The removal of the part funding for the equipment does raise concerns as to the viability of the service for providers and this comes back to the need for a clinical fee that supports the work to be done.

Need for parental engagement and active consent

There are arguments to be made on both sides for the principles of opt in/opt out, although it is notable that opt out is the service that NHS England specified in its original documentation (and is in regular use in vision screening programmes), we understand the need for NHS England to be clear if this is the right route to take.

If the service is to be opt in, then there may be solutions to concerns that this will not pick up children whose parents may be at most risk of overlooking invitations, act in the best interests of children at risk of missing out, and consider ways of making this as efficient as possible so it is not a lot of additional work for schools or providers. In SeeAbility's <u>early work</u> (before the NHS service) we ran an opt in service and on average 80% of parents opt in, which raises the question as to what is happening to the children not seen.

Schools who will have the service will be 'opting in' and so may be in a position to make this clear to parents as part of new starter packs and annual start of year forms that parents are filling in so they can indicate clearly if they want the service, and ensure response on behalf of every child.

In the current model parents are always asked for their child's eye care and general health history and are always asked if they wish to attend their child's appointment – this is part of the specification in use. Offering a 'mutually convenient' appointment may be difficult but choice and an option to change the appointment should always be offered. Logistically the vast majority of SEND parents find it very helpful for the service to be in school alongside many other NHS and local authority services, and for teaching assistants to chaperone their child to the sight test 'in loco parentis'. Our experience with nearly 1000 children was that around 10% of appointments were attended by parents, who are relieved to have a service as accessing GOS or hospital has been too much of a challenge. It is important that parents are not put under undue pressure to attend in person but are engaged in other ways throughout the process if they choose.

Again, in either scenario, it is important that NHS England recognise the additional administration in the fee for the service.

Need for the written report

We agree there needs to be a mechanism for embedding of the vision report into the EHCP and welcome the value NHS England place on report. In our past analysis of Department of Education data only 3% of EHCPs explicitly note visual impairment as a secondary need in this patient population, when the level of unavoidable visual impairment is more in the order of one third.

The writing of the report and engagement with the school professionals is to ensure a child's visual needs and abilities and met and understood. The report should be shared with the family but also the class and more widely where relevant (including with the Qualified Teacher of Visual Impairment speech and language, physiotherapy, occupational therapy). Again this needs to be reflected in the fee for the service.

The relationship with EHCPs is something that we would encourage NHS England to take advice on from organisations such as NatSIP and VIEW, who have worked with the Department of Education in order to embed more understanding of sensory impairment into EHCPs and support the specialist sensory workforce. The review and proposals for a standardised template in EHCPs in the SEND review is a fantastic opportunity to give more profile to vision issues and the specialist VI teaching workforce.

Need for more rigorous analysis and fieldwork before proposals are settled on

We recognise the need to change some aspects of the service which are fully evidence based, but it has been hard to locate the rationale or data behind some of the reasons to change the working model.

Some of the narrative discussion in the document reveals a lack of understanding of the comprehensive and complex needs of the children, the challenges of SEND parenting and the workings of special school life, possibly because the evaluation involved no fieldwork within the school settings in order to see the service first hand. Some areas to highlight where further explanation would help:

- More frequent annual recalls than would be expected in the high street can be explained through the much higher clinical need of these children.
- Past eye care history checks on children were required part of the specification. But as with GOS, this will often rely on parent reported history given difficulties for primary eye care to access shared care records.
- Children with new frames, but no change in prescription, can be explained by the extent of children wearing ill fitting, broken or old frames due to intermittent history of accessing eye care out of school.

There is a case for increased support for all children with learning disabilities to access the eye care they need (this is the pledge in the NHS Long Term Plan), and the expert working group understood the special schools programme was to be the first step in ongoing reform of eye care for people with learning disabilities. For example the creation of community LOCSU easy eye care pathways in every ICS.

We very much encourage NHS England to find a mechanism to continue this important work on reforms, and to make use of the expert advisory offer there is from interested clinicians, professional bodies, charities and school bodies and parent and self advocacy networks.