

Children and young people with vision impairment: The case for transforming support and services in England

Creating the Future Commission, 2021





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Creating the Future Commission

Across England, there are estimated to be 34,000 children and young people with vision impairment and sight loss. As a leading voice and service provider for these children and young people, we know the experience of each of them is unique. But it is also clear to us that there is an urgent need for change across policy areas to ensure people with a vision impairment can lead the life they choose.



In order to come up with a set of recommendations that would transform the experiences and outcomes of children and young people with a vision impairment in England, Guide Dogs established a Commission made up of young people, parents and carers and experts in both policy and practice. The Creating the Future Commission's work has focussed on:

- Understanding the lived experience of children and young people with vision impairment and their families.
- Exploring the things which need to change.
- Shaping policy recommendations to secure better outcomes for children and young people with vision impairment and their parents and carers.

Methodology

The Commission met on a formal basis on four occasions between July and September 2021. In order to ensure the policy recommendations made by the Commission are credible, they designed a process for collaborating with others. This included:

- Commission members undertaking one-to-one discussions with the Commission project team at Guide Dogs.
- The Guide Dogs project team conducted numerous interviews with parents and carers of children and young people with a vision impairment across England, and these were made available to Commission members.

- A series of conversations (in groups and one-to-one) with a wide range of specialists, frontline professionals and stakeholders providing services to children and young people with vision impairment.
- This report also draws on the 2020 research commissioned by Guide Dogs which interviewed 170 parents of children with a vision impairment, setting out a comprehensive picture of the experiences of children and young people growing up with a vision impairment, and that of their parents and carers.

Members of the Creating the Future Commission:

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Lucy Edwards
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Angela Kitching
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Commission members' biographies can be found in Appendix 2.

Addressing the Challenge

The confronting reality is that, despite improvements in some areas of service delivery, there are too many areas where life is much more challenging for people with a vision impairment than for people without such an impairment. Too often, lifelong outcomes in terms of health, employment and other factors reflect the lasting consequences of these early inequalities.

While sighted children learn about movement, mobility and managing the world around them by watching others, children with a vision impairment often need a little extra support.

Accessing services and support at the right time can be a gateway to increasing confidence, happiness and independence in children and young people with a vision impairment and can have a positive impact for parents, carers and families. The support often enables a child or young person to do things that others without a vision impairment take for granted.

In the early years, working with a specialist professional can support a child's physical development, helping them with their posture, crawling or walking. As a child gets older they might need support to confidently run or jump, to navigate streets safely, to prepare food or manage their appearance.

It's not just about directly supporting the child or young person with a vision impairment. Often services are delivered to train or assist those close to the child, so they can help them reach their potential. For example, mainstream or specialist nurseries, schools, FE or HE institutions might need advice on how to help the child or young person access their education in a range of ways. This might include how to adapt lessons or resources or how to use specialist equipment or IT.

To different degrees, children and young people may also rely on ongoing health and social care services to help meet their needs, this is often the foundation upon which other services are built.

Of the 34,000 children and young people in England growing up with a vision impairment, 24,000 of them are under-18. Around 20% of children and young people with a vision impairment have additional special educational needs and/or disabilities (SEND) and 30% have complex needs. Two thirds of childhood vision impairment was present from birth or diagnosed in the first year of life. At a UK level an estimated 0.2% of children and young people up to age 25 have a vision impairment, which is a low incidence, high needs condition.

In addition, an NHS England programme is working to identify a predicted large cohort of children with an undiagnosed vision impairment in both mainstream and special schools. These children are particularly likely to have other special educational needs, and to have a cerebral vision impairment (as opposed to an issue with visual acuity). This is likely to lead to increased demand on an already under-resourced system of support.

Only 62% of young people with vision impairment aged 16-25 were in education or employment compared with 80% of the general population of 16-25 year olds.

The employment rates for young people with vision impairment aged 16-25 are lower than those of their age peers (25.6% vs 54.0%), and the difference is not accounted for by the higher proportion of vision impaired students in education.

Of working age people with sight loss, one in four are employed.

Our research revealed challenges in four major areas:

- 1.** Navigating services, especially in the early stages of a family managing a child's diagnosis.
- 2.** Securing good quality education, including anticipating needs and preventing problems before they arise.
- 3.** Consistent service quality, avoiding any "postcode lotteries" affecting outcomes for children and young people with a vision impairment.
- 4.** Integrating support and services within the wider policy context, and ensuring learning from good practice elsewhere.

Executive summary

Guide Dogs works alongside people with vision impairment throughout their lives. We asked the Creating the Future Commission – a group of young people, parents, carers and professionals working with children and young people with vision impairment – to research and make recommendations aimed at transforming the experiences of accessing services and support for children and young people with a vision impairment.



Some of the most significant findings about the need for change include:

- Experiences of diagnosis are highly variable, with too many parents and carers describing extended periods of uncertainty around the best next steps for their child. Signposting is offered inconsistently across the country.
- There are geographic inconsistencies in accessing services and support which lead to perceptions of an unfair 'postcode lottery'.
- The education and wider support system for children and young people with vision impairment is under-resourced, with a shortage of key professionals.
- The need for a more joined-up service and a single point of information for children and young people and their families has long been recognised as key to improving service delivery and outcomes. Better integration with wider service provision could transform outcomes.
- The Education, Health and Care Plan (EHCP) process continues to present families with huge challenges, typically applying a "deficit model" approach that only releases support when a child or young person has already fallen behind.

- The Commission heard that school staff who are not specialists in Special Educational Needs or Sensory Impairment lack sufficient training about sight loss and vision impairment in a general sense.

We have produced a comprehensive package of recommendations that we believe would positively transform children and young people with a vision impairment's experiences of accessing services and support. The Government's SEND Review creates a unique opportunity for children and young people with vision impairments, and the parents, carers and professionals who work alongside them. We believe this could be the vehicle to deliver some of the recommendations of the Commission. Other areas would require targeted national and/or regional action to ensure the best outcomes for children and young people with a vision impairment.

Summary of recommendations

National action is needed to address the following recommendations:

1.
A universal model pathway should be agreed to secure consistent delivery, access and understanding of the support available for children and young people with vision impairment. The Commission has created a model pathway that we believe should be endorsed.
2.
The Government should commission and publish a new National Strategy for Children and Young People with Low Incidence, High Need Conditions. This should include a National Workforce Plan to ensure the right staff are trained and retained to support these children and young people.
3.
National government needs to ensure local authorities are funded adequately to:
- lead the delivery of a new national offer of family support for children and young people with a vision impairment.
- To provide additional Qualified Teachers of Children and Young People with Vision Impairment (QTVI) and habilitation specialists to avoid excessive caseloads, and establish minimum ratios of number of specialist worker : students.

4.
The Department for Education should set out in detailed guidance what ‘reasonable adjustments’ under the Equalities Act could be in schools, colleges and all education settings.
5.
When the new Specialist Vision Impairment Curriculum Framework is published, the sight loss sector should work in partnership to ensure it is adopted and implemented by each local authority, and that it is formally endorsed by the Department for Education.
6.
A module on basic awareness of low incidence, high needs conditions including vision impairment (both cerebral and ocular) should be included in teacher training, early years professionals’ training and generalist clinician training.

Regional action is needed to address the following recommendations:

7.
Local authorities must prioritise the provision of life changing services such as habilitation and QTVI support.
8.
Each NHS Integrated Care System (ICS) should be mandated to pool local knowledge and existing needs assessments about children and young people with a vision impairment or other low incidence, high needs conditions. This should be the basis of a Local Integrated Plan for Children and Young People with Low Incidence High Needs Conditions, something we believe each ICS should produce.

Thanks and Acknowledgements
Guide Dogs is hugely grateful to the members of our Commission who have been incredibly generous with their time and input, accommodating our meetings and demands around busy professional lives and family responsibilities.

Our Commission members have provided input that has been open about their own experience, and generous in sharing their expertise. As a result, each conversation provided insightful and important input for reflection and policy development. It should be noted that the conclusions and recommendations in this report are that of the Commission, and may not necessarily reflect the views of other organisations Commission members represent or are connected with.

We are also very grateful to the parents and carers who agreed to be interviewed for the project. Many interviewees told researchers difficult stories about their own challenges in accessing support, either for themselves or their children. We appreciate that speaking about these experiences can be challenging and we hope this report and its recommendations can help secure change to improve the situation for other people in similar situations now and in the future.

We are grateful to specialist professionals who have provided advice to the Commission through the course of our work.

1. Navigating services: information, pathways and signposting

The right early interventions to support a child or young person with a vision impairment have the potential to significantly reduce the need for expensive, longer-term interventions into adulthood.



1.1 Navigating the system

Policymakers must focus on early experiences in childhood to make a lasting difference to the outcomes for people with a vision impairment. The outcomes a focus on childhood would impact on are broad and include; mental health, employment and independence.

Parents and carers told the Commission that change was needed across the whole system of support arrangements for children and young people with a vision impairment, from access to services and support to service delivery itself. Many parents and carers said they had led the efforts to identify, research and access support arrangements for their children's vision impairment. Too often, this is difficult and time-consuming, and leads to anxiety and stress. Parents and carers feel they are carrying an immense responsibility and have to "fight" to secure the support to which their child is entitled.

In addition, the Commission heard that services and support arrangements were too often disjointed, lacking in coordination and difficult to access. Parents and carers are left feeling as if they are struggling through layers of bureaucracy to secure appropriate support for their child, with an associated toll on their own wellbeing.

Some charities, including Guide Dogs, have a family support offer for parents / carers, but this is not a universal statutory offering. For those without access to these services, parents and carers can end up juggling their day-to-day life with complex and long running challenges to research and access appropriate support for their child. As children grow up and wish to take on some of the arrangement of their own service provision, these challenges are transferred to them.

Sarah's daughter Erin (7), has Leber Congenital Amaurosis (a condition affecting the retina), nystagmus and myopia. Speaking about the process to secure support Erin, her mum Sarah told us:

"...no-one ever spoke to me about how we were doing or tried to put us in touch with other parents. We've done all that off our own backs. There's no direct focus on us as parents, there's something lacking in the process. It's just as much about support for parents as it is support for the child. If we're not properly supported, how can we properly support her?"

1.2 Information, advice and guidance

The importance of information, advice and guidance cannot be underestimated. High quality information provided at the right time in a child's life helps parents and carers understand their child's diagnosis and its implications, including how to best offer their child support. It can also help the child as they grow to adulthood and need the use of different services.

Information and advice at the point of diagnosis needs to be provided sensitively, acknowledging the need for both practical and emotional support. Research undertaken by Guide Dogs found:

- 68% of respondents agreed that there was not enough support to help parents and carers at the point of diagnosis
- 63% of respondents agreed that the ongoing availability of support and information is an extremely important factor in improving their child's quality of life

- 59% of respondents agreed that access to emotional support to help come to terms with their child's vision impairment was extremely important

1.3 The point of diagnosis

The point of diagnosis of a new condition is a critical juncture for high quality and appropriately delivered information, advice and support. It is an area requiring specific focus and attention. Whilst many parents and carers describe a sense of relief at receiving a diagnosis and knowing that a condition has been identified, many observed that it was difficult to digest the information provided at this point. Some found that doctors and clinicians were reluctant to have conversations about the future or to even acknowledge the life-changing nature of a vision impairment diagnosis for their child.

When diagnosis appointments go poorly, parents and carers may leave without a sufficient understanding of their child's condition. They may not understand its meaning for the long-term. There is an unmet need in the provision of information, advice and support for parents and carers at this point in their child's journey. Information gaps between appointments were also a reported cause of particular worry and stress. Parents and carers were keen to have a clear sense of next steps and to know they could contact clinicians between appointments, which often proves difficult.

Understandably, some parents and carers will respond to this information gap by doing their own research online. One parent commented:

"We felt frightened. What is wrong with our child? Can he see at all? Will he always be like this? What does the future hold for him? Desperate - we needed answers as Dr Google was coming up with all sorts! Where can we go for support."

Parents and carers want to understand the impact of their child's diagnosis on day-to-day activities, education, social relationships and wider wellbeing. Information at diagnosis should equip parents and carers with empowering practical support and, where possible, offers some certainty about the future. It should be delivered empathetically and balance emotional support with practical advice and sign-posting.

Erin's dad, Anthony, underlined the importance of information:

"What is crucial is having information at the right time, when you need it and you're in a position to understand it."

1.4 When it works

Not all experiences of navigating services were negative. Some parents and carers speak very positively about the way in which clinicians gave them the information they needed.

Others explained how senior medical professionals recognised the importance of ensuring parents and carers went away from appointments with clarity on next steps and a strong sense of engagement.

Many children and young people with a low incidence, high need condition like vision impairment will often receive support and interventions from a range of different professionals and service areas. Parents and carers repeatedly mention that a 'map of services' setting out at different services, support options and referral and access routes would be useful. This would recognise the fact that many parents and carers find they have to navigate their way through a complex range of different, sometimes interdependent, services, which can again add to levels of worry and stress.

The importance of information, advice and support for parents, carers and children and young people, at diagnosis and beyond, needs to be better appreciated and understood. The experience of too many parents and carers shows there is a gap here which cannot and should not go unfilled.



2. Getting education right: enhanced support and anticipating needs

Children and young people with a vision impairment told the Commission that they want to grow up enjoying the same opportunities as their sighted peers: pursuing education and learning, exploring life outside the classroom and realising their ambitions for adulthood. Their parents and carers obviously share in these aspirations.



2.1: How schools are supporting children and young people with a vision impairment

Parents and carers need information to empower themselves to make important decisions about education, not least the decision to pursue mainstream or special education options. Progression post-16 and to higher education are also vital considerations for many of the people interviewed for the research.

Concerningly, only 18% of parents and carers said they were 'very satisfied' that the school meets their child's needs and 25% said they were 'very satisfied' with the level of input they have themselves.

Around half the parents and carers asked agreed that schools were using the latest technology to support children with vision impairment and a similar proportion felt there were enough materials in the appropriate formats.

The Commission's research suggests that parents have reservations about the quality of their children's education and the extent to which pupils with vision impairment are supported by appropriately trained staff. This is despite work carried out by the National Sensory Impairment Partnership (NatSIP) in 2018 to provide an Eligibility Framework to help local authorities identify what local sensory services should be providing and on what basis children and young people qualify for support and intervention.

This was backed up by parents and professionals who told the Commission

that in some cases school staff who are not specialists in Special Educational Needs or Sensory Impairment lack sufficient training about sight loss and vision impairment in a general sense. Those staff found it difficult to engage with the specifics of individual children's conditions or needs. This presents an obvious challenge in delivering a fully inclusive education and learning experience.

Amongst parents and carers whose children were receiving support from a QTVI, experience was variable with under-half (47%) saying they were 'mostly satisfied' with the level of support, with concerns about the availability of support being common. Funding constraints may make accessing or increasing the level of support from QTVIs challenging.

When a child or young person is able to access this specialist support, it was noted that it had the potential to transform the experience of education. Specialist one-to-one support was highly valued by the parents and carers the Commission spoke to, who would like to increase their child's access to it.

There was other positive news: 71% of parents and carers agreed that school staff were sensitive to the issues concerning their child's vision impairment and 70% of parents and carers agreed their child's school worked effectively with other agencies to put support measures in place. This is an encouraging sign that schools are engaging in and seeking to provide a joined-up pathway of support. It implies there is effective practice to build on.

2.2 The Education, Health and Care Plan Process

The process to secure appropriate educational support – including via the Education and Health Care Plan (EHCP) route – is consistent with the experience of accessing other services and support: bureaucratic, complex and burdensome for parents and carers. The Commission also finds this approach has fundamental flaws when it comes to meeting the needs of children and young people with a vision impairment.

When a child or young person enters school with a vision impairment, some support needs are relatively easy to anticipate. Too often, however, parents and carers of pupils with a vision impairment end up waiting for their child to fall behind as a result of not having received the support before they are able to apply for an EHCP in order to access it. Using EHCPs as the vehicle for accessing support is unhelpful as it forces the focus onto what the child is unable to do, rather than anticipating the needs early and putting support in place.

Anthony and Sarah – Erin’s parents – spoke to the Commission about the complexity and challenges of the EHCP process:

“Many parents wouldn’t have known about it. We started when she was two and it was only just in place when she started school and took about 18 months to get. We did get what we needed from the EHCP, although it feels like a box-ticking exercise. The whole thing was really demoralising. The EHCP process is really negative, it repeatedly showed what Erin couldn’t do but that’s not how we are as a family, we try to find ways that she can achieve things. It’s a very draining and difficult process.”

Teddy has Alstrom Syndrome, a rare genetic condition which can affect sight. His father Phil, told us:

“I’m a teacher and people have told me that EHCPs are a nightmare. If you don’t get them right, they’re terrible. So I got ahead of the game and took time off so I could chase people. I’ve had nine months of very high stress.”

Bronagh, whose son Eoin has congenital cataracts and glaucoma, told a similar story about the efforts needed to secure an EHCP as a route to support:

“I was lucky that I knew he’d need an EHCP, because nobody instigated that I did it myself. The process is very much parent driven. It shouldn’t be that way, although we have had a family social worker helping for the last few months, but that won’t be for much longer. Then it will be back to beating the drum, which has been really difficult, especially over the last year as Eoin’s needs have become more complex.”

2.3 The reality of self-advocacy

Through the course of the Commission’s work, parents and carers repeatedly spoke about having to battle over long periods of time through multiple formal processes to secure education support, only to then find a system where specialist professionals are overstretched and where the levels of need cannot be met.

Lucy lost her sight aged 17 due to a rare genetic condition, Incontinentia Pigmenti.

Helen, Lucy’s mother, told an all too familiar story about the efforts needed to secure vital education support:

“When Lucy was in the middle of doing her A Levels, the school said they’d not got enough money to support her even though we’d got her statement in place. I had to fight to ensure she had the right support, including reminding them of their legal responsibilities. The downside of that was this may have removed support from others who also needed it.”

68% of parents and carers reported that the attitude and levels of understanding across education professionals about vision impairment was a priority. There is concern about levels of general awareness and understanding and a lack of standardised training for teachers and support staff about teaching children with vision impairment. The lack of consistent provision to address key non-academic curriculum needs in relation to self-advocacy, independent living skills and technology is also problematic.

One young person interviewed said:

“Self-advocacy is the key skill that every student needs – for accessibility needs, mobility support, socialising and building friendships.”

2.4: When it works

We have heard that whilst too many families face arduous battles to secure support, when young people do receive the specialist support they need it has a profoundly positive impact on their development and progression. Kelsey, who is a member of our Commission, and is now studying in his second year at Oxford University spoke positively about the impact the right support can have:

“As a blind young person, I know how crucial the right support is, to guarantee that as many doors as possible are left open during the transition from school education into adulthood and beyond. Now entering my second year at Oxford, I’m grateful for the support that I received during my childhood and teenage years. I’m determined that the same support is available to all young visually impaired people, regardless of their postcode, and that they, along with their families, don’t have to fight to receive it, in the same way my family and I did. Given sufficient levels of the right support are in place, it is evident that visually impaired young people can, and do, succeed.”

For Mia, now 16 and who was born with multiple conditions, including cortical visual impairment, third nerve palsy and photophobia, support co-ordinated and provided by Guide Dogs was transformative.

Mia says:

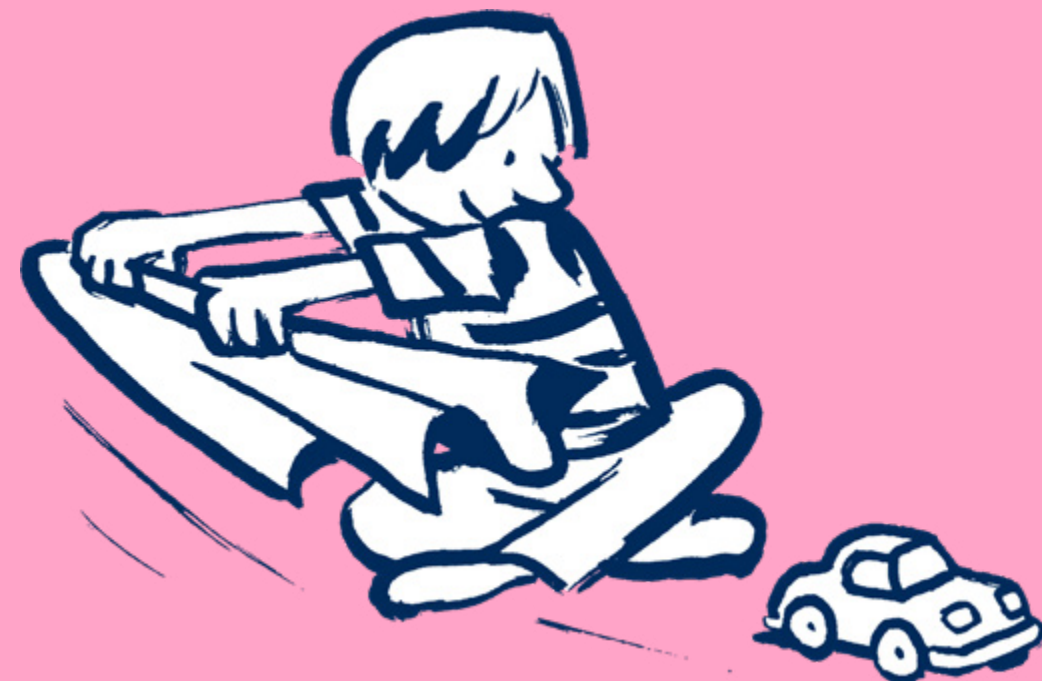
“I was really shy and didn’t go out because I kept falling. Now I have my cane, I have a life. I can go out and get a coffee with my friends.”

“That shy girl has run away and is never coming back – and it’s all because of Guide Dogs.”

Mia’s mum, Bernadette describes the difference Guide Dogs support made in helping to secure a EHCP for Mia:

“Things got really difficult for our family, and we were struggling. That’s when our liaison at the hospital suggested I contact Guide Dogs. They helped us put together an Education, Health and Care plan for Mia, and worked with the local authority to make it happen – it was brilliant! They also supported us when Mia moved to an excellent new school, and helped us find the right assistive technology like Braille readers, to help her do more of the things she loves.”

“I was really shy and didn’t go out because I kept falling. Now I have my cane, I have a life. I can go out and get a coffee with my friends.”



3. The need for consistent access to services, regardless of where you live

The Commission repeatedly heard that availability of services and support should not depend on where you live.



3.1: Impact of the postcode lottery

There are geographic inconsistencies in accessing services and support which lead to perceptions of an unfair 'postcode lottery'.

It is clear a national indicative benchmark of education support staff/ specialist education professionals: student ratio would address this inconsistency in provision and help secure a more equitable educational experience for all children and young people regardless of where they live.

The experience of parents and carers, and the professionals the Commission spoke to, suggests the system is under-resourced, with a shortage of key professionals. This means sustained, one-to-one support is hard to come by. Professionals, including QTVIs and habilitation specialists, can carry caseloads that are too big. As a result, their expertise and time is spread too thinly to be as impactful and effective as it would be ideally.

Bronagh, mother of Eoin, spoke to the Commission about the impact that local service reductions were having:

"Over the years, the team of specialist vision impairment teachers within the city have had their funding reduced to the point where they can no longer provide anything outside direct support within the school and lesson time, whereas before we would have had social time, he would have had scope to have classes around daily living skills"

Of the parents and carers surveyed as part of Guide Dogs research in 2020, more than half (56%) feel that their child is not as independent as possible.

Mobility training and habilitation can lead to higher levels of independence and confidence. 73% of parents and carers reported that mobility training had made their child more confident, and over half of parents and carers felt that their child would have benefited more from their mobility training had they had the same mobility or habilitation worker throughout their school career.

This sense of a 'postcode lottery' is supported by research previously published by Guide Dogs and the Thomas Pocklington Trust in 2020. We found significant inconsistencies in the provision of habilitation across England. There were significant variances; one local authority provided this service to 3% of children and young people with a vision impairment in their area, while another provided this to 47%.

4. Wider policy context

The Commission's work does not exist in a vacuum, it has been mindful of the current policy context which includes potential changes in policy as a result of the awaited SEND Review.



4.1 Learning from others

The Commission also reviewed other work currently taking place across the sight loss sector and wider professional bodies and networks such as the National Sensory Impairment Partnership (NatSIP).

The need for a more joined-up service and a single point of information for children and young people and their families has long been recognised as key to improving service delivery and outcomes. This is a key driver in the Visual Impairment Network for Children and Young People (VINCYP), a Managed Clinical Network established in Scotland in 2014. The VINCYP model is one that has informed our own thinking and provides models of best practice.

The network aims to improve the care for children and young people with a vision impairment. VINCYP involves professionals working in health, education and social work, parents/carers of children and young people with a vision impairment and voluntary sector organisations. Key elements of the VINCYP network include a designated pathway of care, linking medical professionals with specialist education, habilitation services and emotional support for families. The Commission believes there is much to learn from the development of the VINCYP model in Scotland, but there are limitations in direct applicability in England due to different commissioning frameworks and geography. However, we have drawn inspiration from this model in the design of our pathway.

The importance of 'joined up' eye care and health services has been emphasised with the recent launch of National Eye Care Recovery and Transformation (NECRT) Programme and the Elective Surgery Recovery Programme by NHS England. One of the main aims of the programme is to improve equity of access within and between Integrated Care Systems (ICSs) and reduce the backlog of cases. This requires a number of measures including:

- proposals to improve population and needs data
- setting up of an Eye Care Delivery Group
- where not already in place, the creation of an Eye Care Improvement Programme with clinical leads from both ophthalmology, primary care optometry and other specialisations



4.2 Building on strong foundations

The need to provide accessible, relevant and timely support for the families of children and young people has been recognised as crucial. Guide Dogs, RNIB and other organisations developed the 'Starting Point' information leaflet. It was first introduced in 2016 and produced by charities in the sector working alongside a range of eye health and sight loss professionals. The leaflet offers links to helpful resources and emphasises the advantages of early action. It was intended that the Starting Point leaflet would be universally available at the point of diagnosis as an initial form of signposting. The Commission have heard this is not always the case, however.

4.3 The SEND process

With regard to the broader context for special needs in education, the Children and Families Act 2014 set out a presumption that SEN children and young people would be educated in mainstream schools. It established a responsibility for local authorities to identify and monitor children with disabilities or SEN. The same authorities would, the Act confirmed, ensure they have adequate provisions in place to look after these children and would work with local health bodies and others to deliver appropriate support.

There have been criticisms of the SEND process, which resonate with the experience of the parents who took part in our research. In their most recent report, Ofsted said many children and young people are "not getting enough help" in mainstream schools, even when receiving specialist support. The report found specialist support from multi-agency services is "not always timely or implemented appropriately." Further, the report highlighted "long wait times and high levels of bureaucracy" in the Education, Health and Care Plan process, with some families forced to pay for additional services themselves.

The SEND review had not been published in time to be included in this report, and the Commission hopes our recommendations may form the basis for some of the review's conclusions.

Our recommendations for change

The conclusions and recommendations put forward by the Commission are broad in scope. We start from the point that there should be an agreed, universal pathway to help parents, carers and professionals navigate the wide range of life changing services involved in supporting a child or young person with vision impairment. We have proposed an indicative model pathway.

With the numbers of children and young people with sight loss being reasonably low in prevalence (around 0.2% of the total population of children and young people up to the age of 25) we can also see the benefits of drawing together learnings from other low incidence, high needs conditions to drive up standards for all. This work should be supported by national and regional commitments from policy makers.

To secure better outcomes through universally available support and improved coordination across services for children and young people with a vision impairment, additional government funding will be needed. By ensuring appropriate support and better outcomes for children and young people with vision impairment, inequalities around employment and social inclusion amongst this group will be lessened.



Recommendations

National action is needed to address the following:

1. A universal model pathway should be agreed to secure consistent delivery, access and understanding of the support available for children and young people with vision impairment.

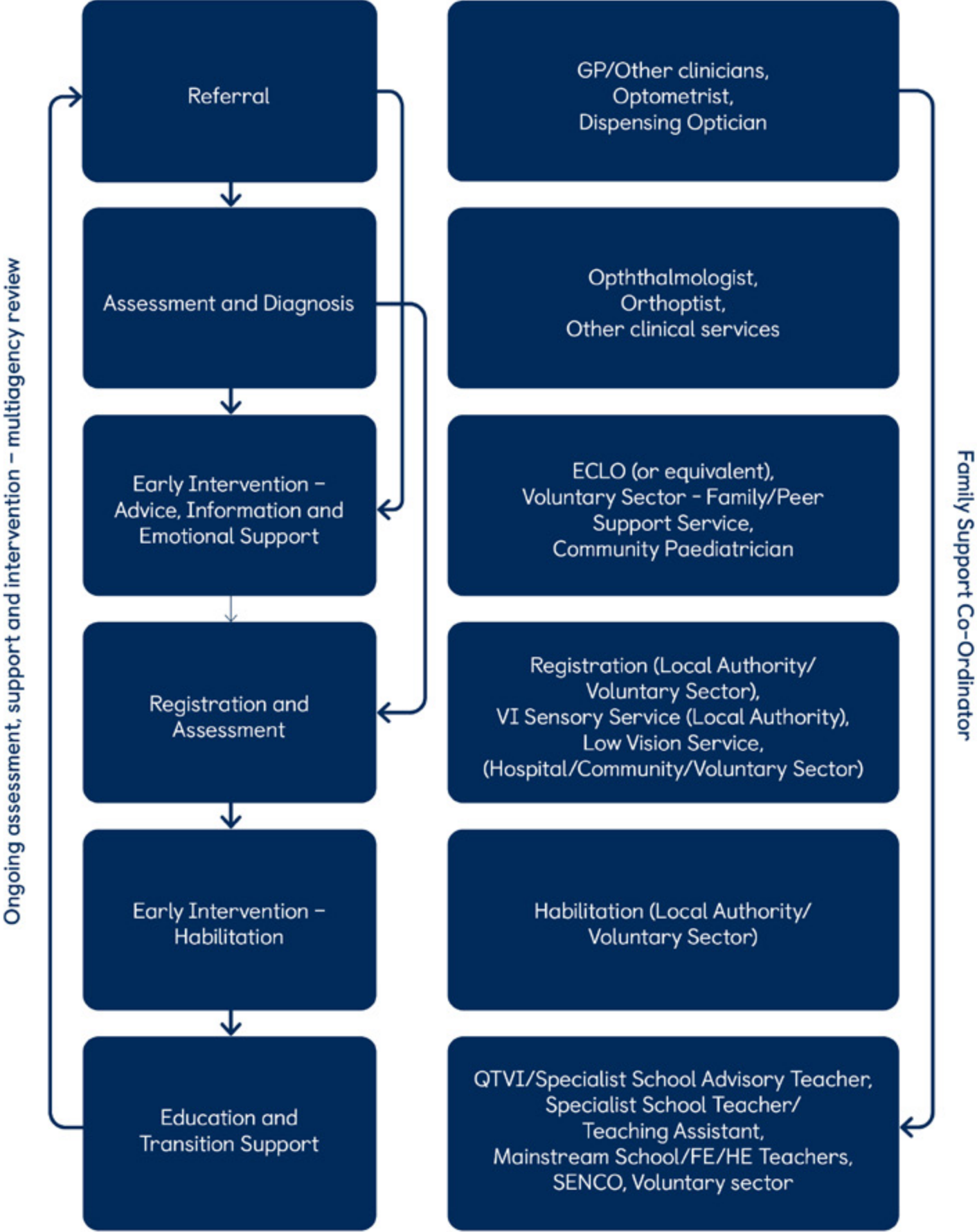
An agreed, flexible and responsive pathway would help children and young people and their parents understand the support they can receive, and how to navigate the system. To this end, we have designed a new pathway that forms the basis for our thinking in this area, and our recommendations.

It should be noted that given the nature of eye conditions and how conditions are diagnosed this pathway is not a linear journey for most children and young people. The entry and exit points for different children and young people will vary and could be multiple depending on individual conditions and need. This is reflected in our pathway.

For children and young people with additional needs including learning disabilities and neurodevelopmental impairment, a vision impairment can be identified much later. A seamless interaction between the vision impairment pathway and other pathways of support for different needs should therefore be a primary goal of delivery.

Figure 1: illustrative pathway of support for children and young people with vision impairment, setting out how different services interact and how a new Family Support role could provide important support to parents and carers across and throughout this pathway.

If you are using a screen reader, please follow this link to a text description of Figure I.



2.
The Government should commission and publish a new National Strategy for Children and Young People with Low Incidence, High Need Conditions. This should set out how standards and outcomes across all low incidence, high need conditions will be improved. Through the course of our work it has become clear that many of the challenges facing children and young people with vision impairment are shared by other children with low incidence, high needs conditions. To drive up standards and outcomes, government should draw on existing best practice for different condition-specific groups. The Government should work with people with lived experience and frontline professionals involved in providing services and support.

We are not recommending the introduction of minimum standards in this area, as we would not want to remove any of the services or support that is in place for any of these groups. Instead, standards for all should be driven up by sharing, replicating and learning from best practice that exists for children and young people with a range of conditions. A one size fits all approach would not work given the complexity of some conditions. Nonetheless, there is much to gain by giving smaller cohorts greater profile in policy making by grouping them together.

This work should be driven by a new National Workforce Plan for Children & Young People with Low Incidence, High Need conditions which complements the new National Strategy we propose. The National Workforce Plan should establish the numbers of specialised professionals across health, education and wider services needed to secure the minimum ratios of provision developed with frontline professionals and the actions Government will take to train, recruit and retain professionals across all these key service areas. The Workforce Plan should support efforts to ensure all specialised services are available on a universal basis in all parts of the country and can meet levels of need.

3.
National government needs to ensure local authorities are funded adequately to:
- Lead the delivery of a new national offer of family support for children and young people with a vision impairment.
- Provide additional specialist professionals such as QTVIs and habilitation specialists to avoid excessive caseloads for individual professionals.

Family Support: An offer along these lines already exists in some areas (with a range of different names and linked to a range of professionals including habilitation professionals, ECLOs and QTVIs). Universal access to this offer across England has the potential to transform the way children, young people and their families access both practical and emotional services and support.

The role needs to provide an understanding of the range of services and support available from different clinicians and professionals across the statutory and voluntary sector. Each ICS should ensure they are transparent about publishing where this universal service offering is situated (ie what professional it can be accessed through).

Additional Specialist Professionals: Government should work with frontline professionals to establish indicative minimum ratios of specialist professionals: to those in receipt of support to secure accountability and a baseline level of provision.

We believe that all children and young people requiring the support of a QTVI – and other specialist support – should have universal access to that support regardless of their education setting (mainstream school; special school; or further education college).

4.
The Department for Education should set out in detailed guidance what ‘reasonable adjustments’ under the Equalities Act could be in schools, colleges and all education settings. This would ensure children and young people would not necessarily have to receive an EHCP in order to receive the support they need.

If the government were to clarify and expand the existing guidance on what is meant by ‘reasonable adjustments’ in an education context, we believe schools, colleges, local authorities and parents and carers could use this as a lever to open up services and support to children and young people with a vision impairment at the point of need, rather than waiting for them to fall behind. The starting point for this work should be expansion of the Equality & Human Rights Commission’s guidance on Reasonable Adjustments for Disabled Pupils.

This would have benefits for children and young people other than those with a vision impairment; this recommendation is supportive of the work of the National Deaf Children’s Society (NDCS) in this area.

5.
When the new Specialist Vision Impairment Curriculum Framework is published, the sight loss sector should work in partnership to ensure it is adopted and implemented by each local authority, and that it is formally endorsed by the Department for Education.

The importance of a specialist curriculum framework for vision impairment education addressing the development and learning needs associated with blindness and partial sight and which reflects the distinctive skills required by learners with vision impairment is widely recognised within the vision impairment education field.

At present, there are several specialist curricula and outcomes frameworks for children and young people with vision impairment being used in the UK, none of which has any statutory status. Having a range of curricula and outcome frameworks can lead to a lack of clarity about what should be taught, when and by whom, and this accompanied by the lack of a shared vocabulary, can make it difficult to communicate to the non-specialist education sector the need for these skills to be taught.

6.
A module on basic awareness of vision impairment (both cerebral and ocular) should be included in teacher training, early years professionals’ training and generalist clinician training.

The training should cover signposting information to parents and carers on routes into services and support. This would help ensure a more informed approach to conversations involving frontline professionals and would contribute to securing a more inclusive experience across education – and in other areas – for children and young people with vision impairment. We believe this could be part of basic awareness of other low incidence high needs conditions, in order to raise standards for all. This training would not replace the specialist training and mandatory qualifications required by specialist professionals but would be aimed at the wider education, health and associated workforces.

Regional action is needed to address the following:

7.
Local authorities must prioritise the provision of life changing services such as habilitation and QTVI support. While we recognise this area needs national government investment, the differences in availability of services across England must not be overlooked, and local authorities should play their part in ensuring access to these services.

8.
Each NHS Integrated Care System (ICS) should be mandated to pool local knowledge and existing needs assessments about children and young people with low incidence, high needs conditions to ensure good understanding on a system-wide basis. This will ensure planning and commissioning decisions are made with accurate data and the needs of the local population in mind. We would suggest that this work is routed through each ICS’s Eye Care Delivery Board (or equivalent) and is led by a nominated senior responsible officer or clinical lead.

9.
Building on this local intelligence and data, we believe each local area should produce a Local Integrated Plan for Children & Young People with Low Incidence, High Needs conditions. These local plans should set out how different services and agencies will work together to drive up standards and improve outcomes. We are keen to establish a degree of uniformity across England by the adoption of a pathway for children and young people with low incidence, high needs conditions, but we recognise that each local offer will differ due to variances in population, geography and available services.

Local authorities should develop this Local Integrated Plan in partnership with the ICS in their area and we propose these local plans are agreed by each local authority’s Health & Wellbeing Board. To ensure these plans can become properly embedded and merged into NHS and local authority commissioning cycles, the plans should be produced to cover a three year period with annual reports on delivering against national standards and locally agreed targets and outcomes presented to the Health & Wellbeing Board; NHS trust boards; and relevant local authority scrutiny committees. Central to these local plans should be a specific focus on strengthening practical and emotional support for parents and carers and families.

Appendix 1

Members of the Commission



Dr Martin Edobor FRSA MRCGP

Martin is the Chair of the Fabian Society and Clinical Director of North Newham Primary Care Network. He is an NHS General Practitioner in east London and the Lead for Newham Improvement and Innovation Hub promoting quality improvement across primary care in Newham.

He is completing a part-time Masters in Social Innovation at St Edmund’s College, Cambridge and Cambridge Judge Business School after being awarded a Social Innovation Scholarship in 2020. He is a fellow of the Royal Society of Arts and Member of the Royal College of General Practitioners



Lucy Edwards

Lucy is a professional broadcaster and presents regular reports for the BBC on TV and radio and has an ever-growing portfolio of work. She constantly works to promote disability issues and has overcome her own adversity to show the world that there is life after sight loss.

Lucy has most recently collaborated with Guide Dogs UK to create an educational YouTube video series named, ‘Blind Hacks’ which explores aspects of life as a blind person in 2019.



David Holloway

David Holloway is Senior Policy Manager for SEND at the Association of Colleges where he works on behalf of member colleges including general further education colleges, sixth form colleges and specialist colleges. He has more than 20 years’ experience in the college SEND sector as a teacher, teacher trainer, and manager of both discrete and mainstream SEND provision.



Angela Kitching

Angela works for a national charity as a campaigner and is Vice Chair of Contact, the charity for families with disabled children. She is passionate about using her skills and experience to change health and social care systems to benefit their users. Angela has two children, one of whom has complex disabilities including severe cortical visual impairment, and the family has extensive experience with paediatric health, social care and education settings. Her son has received support from a qualified teacher of the vision impaired, Early Years VI practitioner, an Occupational Therapist and now attends a specialist school.



Professor Rachel Pilling

Rachel has been a consultant paediatric ophthalmologist at Bradford Teaching Hospitals NHS Foundation Trust since 2010 and was appointed as Professor of Special Needs and Learning Disability Eye Care by the University of Bradford in 2020.

She has been involved with learning disability eye care for over ten years, initially as a member of the Royal College of Ophthalmologists Working Party and subsequently member and chair of the VISION2020UK Learning Disability committee. In 2016 she was awarded the Astbury Award in recognition of her collaborative work in Eye Care for people with Learning Disability.

She is clinical lead for NHS England Special School Eye Care Programme which is introducing visual assessments annually for all children attending special schools in England.

She has published widely on aspects of eye care for learning disability in particular special school visual assessment, cataract surgery and diabetic retinal screening, and has developed a tool for visual assessment for people with complex needs, the Bradford Visual Function Box.

Rachel is an Associate of the CVI Society. Her current research interests include the use of colour tents to support visual development in children with severe cerebral visual impairment and creating simple tools for communicating the strategies which help the child with CVI, for use by parents, teachers and QTVI. Together with fellow paediatric ophthalmologists she is leading on the development of a national clinical assessment protocol for cerebral visual impairment for the Royal College of Ophthalmologists.



Caireen Sutherland

Caireen is a qualified teacher with the mandatory qualifications for vision and multi-sensory impairment and has been working in the field of SEND since 1999. She currently works as Principal Education Officer at the RNIB. She has previously worked in Local Authority Sensory Support services, for Sense and as a freelance consultant.

Alongside her role with RNIB Caireen continues to maintain some consultancy work, working with children directly and/or settings to ensure best practice and provision for young people with sensory impairments.



Kelsey Trevett

Kelsey is an under-graduate at the University of Oxford studying Politics, Philosophy and Economics. He attended a mainstream primary and secondary school before studying for his A Levels at the specialist Royal National College for the Blind. Kelsey has received a range of specialist support including habilitation support and was matched with his guide dog Lacey aged 15. Kelsey became blind aged five due to cancer and has no vision.



Anthony & Sarah Williams

Anthony and Sarah’s daughter Erin is six years old, and this year was matched with her buddy dog Quince and attends a mainstream primary school where she is learning to read enlarged text alongside learning to read Braille. Erin receives support from a Guide Dogs habilitation officer through her council and her buddy dog Quince also provides her support. Erin has nystagmus and retinal dystrophy which mean she is registered severely sight impaired. They have worked with several different organisations to help make sure that their daughter is successful and has the same opportunities as her sighted peers. This includes Guide Dogs through the mobility services that they provide to Gloucestershire Council as well as the Advisory Teaching Service at the Local Authority.

Anthony is an electrical engineer and Sarah is a teacher for children with special needs in Gloucestershire.



Angela Wood

Angela was appointed Executive Chair for Habilitation VI UK in 2019 and her role involves developing the membership and national standards of practice for the largest organisation network of Habilitation Specialists in the UK.

She has worked within the field of visual impairment for over 30 years and is a registered Qualified Habilitation Specialist and Qualified Rehabilitation Officer.

Angela has worked within several sensory support services in the Midlands and southern areas of the UK, delivering key independence services and training to support adults, children and young people with a vision impairment. For the past 10 years, Angela has been working for Dorset Council, developing and delivering Habilitation Services across Dorset, Bournemouth, Poole, and Christchurch.



Appendix 2

Glossary of key terms

Cerebral Vision Impairment:

Cerebral visual impairment (sometimes called cortical visual impairment or CVI) is a disorder caused by damage to the parts of the brain that process vision. It’s most common in babies and young children but can continue into adulthood.

Education, Health and Care Plan (EHCP):

An Education, Health and Care Plan is for children and young people aged up to 25 who need more support than is available through special educational needs support. EHCPs identify educational, health and social needs and set out the additional support to meet those needs.

Eye Clinic Liaison Officers (ECLO):

ECLOs act as an important bridge between health and social services and are central to the support and wellbeing of patients in eye clinics.

Equality Act 2010:

The Equality Act 2010 legally protects people from discrimination in the workplace and in wider society. It replaced previous anti-discrimination laws with a single Act, making the law easier to understand and strengthening protection in some situations. It sets out the different ways in which it’s unlawful to treat someone.

Habilitation:

Habilitation involves one-to-one training for children and young people with a vision impairment. Starting from their existing skills, it aims to develop their personal mobility, navigation and independent living skills. At whatever age the training is started, the overriding goal is to maximise the child or young person’s independence, opening the way in the future, to further study, employment and an independent life. Habilitation support is provided by specially trained habilitation professionals.

Health and Wellbeing Boards:

Health and Wellbeing Boards were established under the Health and Social Care Act 2012 to act as a forum in which key leaders from the local health and care system could work together to improve the health and wellbeing of their local population.

Low incidence, high need conditions:

The term ‘low incidence’ is used to describe needs that occur less frequently and may require a more specialised response.

NHS Integrated Care System (ICS):

Integrated Care Systems (ICSs) are partnerships between the organisations that meet health and care needs across an area, to coordinate services and to plan in a way that improves population health and reduces inequalities between different groups.

Qualified Teacher of the Visually Impaired (QTVI):

Specialist teachers who have additional, mandatory qualifications in teaching children and young people with a visual impairment.

SEND: Special Educational Needs and Disabilities Special Educational Needs Co-ordinator, (SENCO):

Special Educational Needs Co-ordinator, is the school teacher who is responsible for assessing, planning and monitoring the progress of children with special educational needs and disabilities.

Specialist Vision Impairment Curriculum Framework:

A collaborative project funded by RNIB and supported by Guide Dogs, Thomas Pocklington Trust and others. The framework aims to provide the foundations for children and young people to achieve their educational outcomes through a consistent and universal approach. Education professionals will have access to a central resource hub of peer reviewed materials.

Vision impairment:

Vision impairment occurs when a person has sight loss that cannot be corrected by using glasses or contact lenses. It means that at least one function of the eye or visual system is limited. The most common impairments are of visual acuity (sharpness or clarity of vision), visual fields (the ability to see around the edge of your vision while looking straight ahead), contrast sensitivity, and colour vision.

People in receipt of a **Certificate of Vision Impairment (CVI)** are classified either as being as Severely Sight Impaired (blind) or Sight Impaired (partially sighted).

Appendix 3

Text description of Figure 1

Figure 1 sets out an illustrative model of what a renewed pathway could look like. There are two columns, each containing six boxed categories. The column on the left describes points in the pathway and the column on the right contains the titles of professionals involved at each point.

On the left-hand column there are a series of arrows, connecting various stages of the pathway to illustrate possible journeys for service users. The illustrative use of arrows is show that the pathway is not a linear process: children and young people may enter and exit the pathway at different points, potentially multiple times.

The figure is encircled by two arrows, moving in a clockwise direction to suggest a process of on-going assessment, support and intervention; a process that is supported by a Family Support Co-ordinator.

Each point in the pathway is described below along with a list of relevant professionals.

- Step 1: Referral.**
GP/clinicians, Optometrist and Dispensing Optician.
- Step 2: Assessment and Diagnosis.**
Ophthalmologist, Orthoptist and Other clinical services
- Step 3: Early Intervention, Advice, Information and Emotional Support**
ECLO (or equivalent), Voluntary Sector - Family/Peer Support Service Community Paediatrician
- Step 4: Registration and Assessment**
Registration (Local Authority/ Voluntary Sector), VI Sensory, Service (Local Authority), Low Vision Service (Hospital/Community/ Voluntary Sector)
- Step 5: Early Intervention – Habilitation**
Habilitation (Local Authority/ Voluntary Sector)
- Step 6: Education and Transition**
QTVI/Specialist School Advisory Teacher, Specialist School Teacher/ Teaching Assistant, Mainstream School/FE/HE Teachers, SENCO, Voluntary sector

Users of screen readers, please follow this link to return to the main document.

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