Guide Dogs

CLINICAL COUNCIL
FOR EYE HEALTH COMMISSIONING

The eye care support pathway for children and young people with a vision impairment

England

Contents

Endorsements

abdo
Association of British Dispensing Opticians

Association of Optometrists

BAME
VISION
Supporting ethnically diverse communities with their eye health and sight loss

BIOS
British and Irish Orthoptic Society

CLINICAL COUNCIL
FOR EYE HEALTH COMMISSIONING

THE COLLEGE OF OPTOMETRISTS

Esme's Umbrella
FOR EVERYONE WORKING FOR THE GREATER AWARENESS OF
Charles Bonnet Syndrome

FODO
The Association for Eye Care Providers

Glaucoma UK

HabVIUK

LOCSU

Look

Macular Society
Beating Macular Disease

NatSIP
National Sensory Impairment Partnership

Rehabilitation Workers Professional Network

RETINA UK
WORKING FOR PEOPLE WITH INHERITED SIGHT LOSS

RNIB
See differently

The ROYAL COLLEGE of OPHTHALMOLOGISTS

RSBC
Royal Society for Blind Children

SEE ABILITY
Live. Love. Thrive. Belong.

TPT
Thomas Pocklington Trust

victa
EMPOWERING BLIND CHILDREN YOUNG ADULTS

view

Visionary

Foreword

Andrew Lennox

Chief Executive Officer, Guide Dogs

I'm delighted to introduce you to the eye care support pathway for children and young people with a vision impairment. Designed to sit alongside the adult eye care support pathway, it is the result of combined efforts from across the sight loss sector, with extensive input from clinicians, charities, parents, young people and specialist professionals.

Receiving a vision impairment diagnosis can be an overwhelming experience, suddenly opening up a whole world of new terms, organisations and services as parents and young people try to access the support they need. The pathway aims to help families and professionals so that children get the right support at the right time and no young person is held back by their vision impairment.

Thank you to all our partners, contributors and volunteers who helped bring this pathway together.

Louisa Wickham

National Clinical Director for Eyecare, NHS England

NHS England welcomes the creation of this eye care support pathway for children and young people with a vision impairment. This will support individuals and families to fully understand their journey and will empower them to receive the best care possible. It will also be a vital tool for practitioners, setting out a model of what good practice care and support looks like from the perspective of those receiving it.

Wojciech Karwatowski

Chair of the Clinical Council for Eye Health Commissioning

The Clinical Council for Eye Health Commissioning is delighted to have collaborated with our partners from across the vision impairment sector to help shape and define this pathway. As well as providing an essential guide for families, the pathway will act as a benchmark for all those involved in the commissioning and delivery of services for children and young people.

From first identifying a possible eye condition, right through to living well with vision impairment, it sets out what families should come to expect and helps practitioners ensure they meet children and young people's individual needs.

Taken together with the adult eye care support pathway, we now have a comprehensive framework of support for families and individuals, vital tools to help us improve outcomes for all.

Introduction

This pathway for children and young people with a vision impairment in England intends to support children, young people and their families on their journey from initially noticing a possible eye condition, through to living well with vision impairment. It is designed to provide a clear outline of what support children, young people and their parents can expect and when, and to empower them with knowledge and confidence to ensure they get the support they need.

In addition, for health, education and social care professionals and commissioners, the pathway provides an overview of what good practice care and support looks like from the perspective of those receiving it.

It brings together the NHS healthcare support journey with wider social and educational services, providing an example of the typical pathway and support a child or young person might experience, up to their transition to adult services. After transitioning to adult services, the adult eye care support pathway, developed by RNIB and partners, can continue to support people on their journey.

This guidance was developed in collaboration with health, education and social care professionals, children and families, and experts from across the charity sector.

For the purposes of this pathway, the term ‘vision impairment’ refers to a vision impairment in both eyes that cannot be fully corrected using prescription glasses or contact lenses.

Each child and family’s experience will differ depending on the condition and their individual circumstances. The local services available to them may also differ. The timelines given in the pathway reflect those set out in existing guidance, but actual timings may vary depending on local circumstances. Children and young people may also enter, leave and re-enter this pathway at different stages, depending on their circumstances and vision impairment.

Many children and young people with vision impairment may also have additional support needs and requirements alongside their vision impairment. For children and young people with additional disabilities and complex needs, a vision impairment may be identified much later. They may also be following other health and support pathways for these conditions at the same time, which may impact on their eye care journey.

This guidance is based on findings from Guide Dogs’ Creating the Future Commission, which recommended the creation of a universal pathway to help children and young people, parents, carers and professionals navigate the wide range of services involved in supporting someone with a vision impairment.

How to use this guidance

The pathway

The pathway is divided into four stages:

- Having the initial appointment
- Having the diagnosis confirmed
- Support after diagnosis
- Living well with a vision impairment

Each section outlines the expected chronological support journey for a child or young person, from when a possible vision impairment is identified, through to living well with vision impairment.

For children, young people and their families, this is designed to be used as a guide, ensuring that they are aware of the care and support that is available to them and that they are entitled to.

For health, education and social care professionals and commissioners, the pathway sets out when children, young people and families should be signposted or referred to other forms of support, helping them navigate through a complex system and ensuring the provision of integrated care.

A glossary of terms can be found on page 31.

Support requirements

Each stage of the pathway is accompanied by 'support requirements'. Developed with children, young people and their families, these set out what someone should know and feel at each stage of the pathway. These are called 'support requirements' as they give an overview of the level of knowledge, information and confidence that could be experienced by someone who feels fully supported in their journey.

The support requirements are split into three categories: 'the journey', 'the eye condition' and 'getting support'. These categories align with those that are included in the adult eye care support pathway. Each category is also then divided into three additional sections, which are relevant to that stage of the pathway.

For children, young people and families, they provide an overview of what support and information they should expect. They can use these requirements to ensure they are receiving this support.

For health, education and social care professionals and commissioners, the support requirements are a tool to ensure that they are meeting the support needs of the child, young person, and their family, and that these are central to their decision-making process.

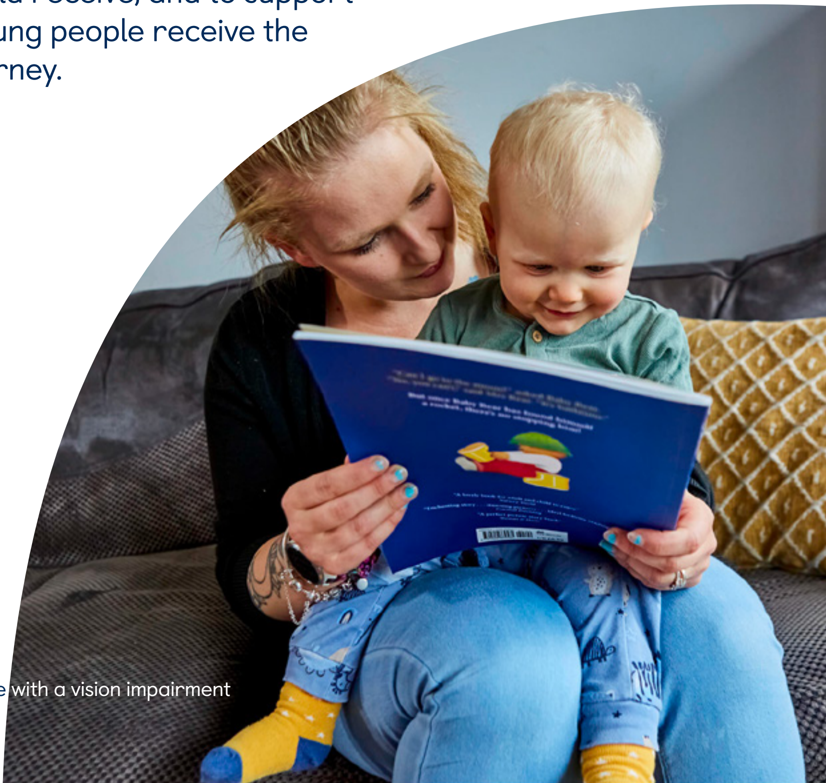
Standards and guidance

The standards and guidance provide examples of the standard of care and support people should expect. These have been taken from existing professional standards and guidance from organisations such as The Royal College of Ophthalmologists, The College of Optometrists, and the National Institute for Health and Care Excellence (NICE). These are referenced in full on page 33.

We consulted with sector experts to select a range of standards and guidance to illustrate the level of support families should be able to expect at each stage of the pathway. The pathway aims to embed information, advice and support for children and young people across the eye care journey. For this reason, these are non-clinical standards and guidance and represent just some examples of standards of care. The reference section provides details of where the original standards and guidance can be found.

For children, young people and their families, the standards and guidance provide a benchmark against which parents and carers can assess the support their child is receiving. For health, education and social care professionals and commissioners, they provide a clear set of guidelines and best practices to ensure that they can deliver consistent and high-quality care to children and young people with a vision impairment.

Taken together, the pathway, support requirements, and standards and guidance aim to help families access person-centred care and understand what support they should receive, and to support professionals to ensure children and young people receive the right support at every stage of their journey.



The eye care support pathway for children and young people with a vision impairment

Stage 1:
Having the initial appointment

Stage 1: Having the initial appointment

The 'initial appointment' section of the pathway covers the period from when initial concerns about the vision of a child or young person are raised, through to their referral and first appointments with specialist eye care practitioners.

This stage has three parts:

- **Part 1:** The eye care support pathway
- **Part 2:** Support requirements
- **Part 3:** The standards and guidance

▼ **Part 1:** The eye care support pathway

1	Concerns about the child or young person's vision are noticed or known and are brought to the attention of primary eye care professionals, for example through a sight test at a local optical practice (such as an opticians), or consultation with a health professional such as a General Practitioner (GP) or Health Visitor. Sight tests for children are covered by the NHS.
2	If the concern cannot be corrected by primary eye care, they will then be referred to an NHS eye service, such as the hospital eye clinic. Alternatively, they may be referred directly to the hospital eye clinic by a health professional such as a GP, paediatrician, or Health Visitor.
3	Following the referral, they will receive communication and confirmation of the appointment. The appointment is expected to take place within a maximum of 18 weeks.
4	The appointment will take place with eye-care practitioners, which may include a specialist ophthalmologist, to discuss the potential diagnosis.
5	At the appointment, they will receive a selection of appropriate tests which will help healthcare professionals to reach a diagnosis on the condition. These tests may involve several health professionals and could take a couple hours or longer, or involve multiple visits.
6	They start to receive support from an Eye Care Liaison Officer (ECLO), if available from the hospital, who will support them throughout their journey.
7	They will be referred to a low vision clinic to receive low vision aids and support.
8	Alongside this, there will be signposting or referral to community groups and local and national charities as needed, who will be able to provide practical and emotional wellbeing support for the child, young person and their family while waiting for information.

▼ Part 2: Support requirements

Being referred to an eye-health specialist	
The journey	• I know how to inform healthcare professionals at the appointment of other conditions or additional needs I/my child might have. • I know how to access primary eye care for myself/my child, such as through a local optical practice, that will identify the need for referral to a specialist.
The eye condition	• I am aware that I/my child may have an eye condition.
Getting support	• I know who to contact if I have any questions about the appointment ahead of or following the appointment. • I know what to do if there is a change in my/my child's eye condition whilst I am waiting for an appointment.

Receiving communication about the appointment	
The journey	• I understand who the appointment is with and what assessments will take place. • I understand that I/my child may not be assessed right away at the hospital, and that there may be a need to wait.
The eye condition	• I understand I am/my child is yet to have any confirmed information on the suspected eye condition.
Getting support	• I know where to go for practical support and information about the appointment.

Having an appointment with a specialist ophthalmologist	
The journey	• I am prepared for the appointment at the hospital and know what to ask about. • I am/my child is spoken to directly, if appropriate, rather than exclusively through parents/carers. • I am spoken to in plain language and in a manner I understand.
The eye condition	• If applicable to my situation, I understand that I can delay assessment for an official diagnosis if it is in my/my child's best interest (in some cases, diagnosis can be a complex process and may not occur in the first appointment).

Having an appointment with a specialist ophthalmologist continued…	
Getting support	• I/my child has been given the opportunity to ask questions. • I understand what practical, emotional and wellbeing support is available from my local authority, primary care and the voluntary sector. • I feel confident explaining everything to my child in language they will understand. • I understand how the support I am/my child is receiving interacts with any other support and pathways being followed for any additional conditions I/my child may have. • I have had the opportunity to speak with an ECLO if one is available in my area.

▼ Part 3: The standards and guidance

Standard/guidance source	**Detail**
The Royal College of Ophthalmologists	In each hospital eye department, there is an ophthalmologist with an identified role for children/young people with a vision impairment. [A]
The UK Ophthalmology Alliance	In-clinic, waiting times should be kept to a minimum and patients are kept informed on the day of current average waiting times. [B]
The UK Ophthalmology Alliance	Staff avoid jargon, explain unfamiliar terms, and confirm understanding by asking questions. [B]
The Royal College of Ophthalmologists	Children and young people are seen within a dedicated paediatric clinic, unless the nature of the condition requires more specialist treatment. [A]
The Royal College of Ophthalmologists	Parents/carers are supported and encouraged to advocate for their child's care by providing information and social and emotional support. [C]
The UK Ophthalmology Alliance	Adjustments should be made to ensure that physical or learning disabilities, sight, speech, hearing and reading difficulties, or challenges with understanding or speaking in English do not limit the patient's participation in consultations and their care. [B]
The Royal College of Ophthalmologists	As outpatients, children, young people and their families should have access and involvement in open discussions on their care and condition. [C]
NatSIP	There are clear routes in place for referring children and young people for specialist emotional wellbeing and mental health assessment, and/or specialist social care assessment if issues with social and emotional wellbeing become apparent. [D]

Standard/guidance source continued…	**Detail continued…**
The UK Ophthalmology Alliance	Hospital eye services provide access to Eye Care Liaison Officers. [B]
The College of Optometrists	A patient cannot be refused to be seen by an optometrist based on their age alone. A transfer of care or a referral should be arranged if a specialist assessment is in the patient's best interests. [E]

Your notes

The eye care support pathway for children and young people with a vision impairment

Stage 2:

Having the diagnosis confirmed

Stage 2: Having the diagnosis confirmed

This section covers the period from when the child or young person receives their diagnosis, through to their referral to local clinical and social support. It also looks at the process for completing a Certificate of Vision Impairment (CVI), where appropriate.

This stage has three parts:

Part 1: The eye care support pathway

Part 2: Support requirements

Part 3: The standards and guidance

▼ Part 1: The eye care support pathway

1	The child or young person and their parent/carer receives their diagnosis and treatment plan. In some cases, such as when the child or young person has additional needs and conditions, diagnosis can be a complex process and may not occur in the first appointment. However, a later diagnosis should not affect the support that is offered.
2	They will continue to receive regular support from the eye clinic and local optical practice, as needed. If they have not already, they may be referred to the low vision clinic by an ECLO or the team at the hospital.
3	If eligible, and with family consent, the ophthalmologist fills in a Certificate of Vision Impairment (CVI) to indicate whether the child or young person is 'sight impaired' or 'severely sight impaired'. A copy is given or sent to the patient or parent/carer.
4	They will be referred to local authority vision impairment services where appropriate and with parental consent, including the local inclusion support services, who provide support at home and in education settings.
5	There will be ongoing engagement with the low vision clinic, who will provide support such as low vision aids as needed, and with community groups and local and national charities as needed.

▼ Part 2: Support requirements

Receiving a diagnosis	
The journey	• I understand the full process of diagnosis and the next steps of how the condition will be treated and managed. • I feel the diagnosis was handled empathetically and honestly.

Receiving a diagnosis continued...	
The eye condition	• I understand what condition I/my child has. • I understand that, as things progress, further conditions may be identified and diagnosed. • I understand what Charles Bonnet Syndrome is and how it might affect me/my child.
Getting support	• I know where to get practical support and information for myself/my child on the eye condition. • I have been referred to local inclusion support services for support in education settings. • I know how health and low vision services can support me/my child.

Processing the diagnosis	
The journey	• I have been offered emotional support and know how to get help if I need it.
The eye condition	• I understand how the condition may develop. • I understand how the condition may be associated with or impact other conditions or additional needs. • I understand if the condition is hereditary and what that means. • I understand that the condition may affect education, learning and development.
Getting support	• I know about community organisations and local and national charities that can support people with my/my child's condition and/or emotional wellbeing support.

Managing the condition	
The journey	• I understand how the condition will be managed, how many appointments I should expect and where they will be. • I have been directed to reliable sources of support, such as eye condition specific charities.
The eye condition	• I understand how the condition may affect my/my child's vision in the future. • I understand the importance of following the treatment plan. • I understand the treatment or management options. • I know how to recognise if the eye condition changes and what to do if it does.

Managing the condition continued…	
Getting support	• I know I can go back to an ECLO or the low vision clinic for support if one is available in my area, and how to do so. • I understand what eye care professionals are involved in my/my child’s treatment, and why. • I am confident I/my child can still receive clinical support without a confirmed diagnosis. • I have been provided with accessible and appropriate information on, and where appropriate a referral to, local community support groups and sight loss charities. • I understand how the support I am/my child is receiving interacts with any other support and pathways being followed for any additional conditions I/my child may have.

▼ Part 3: The standards and guidance

Standard/guidance source	Detail
The Royal College of Ophthalmologists	Copies of clinic letters are routinely provided to parents and young people in the correct format unless there is a specific concern it may be harmful. [A]
The Royal College of Ophthalmologists	The hospital experience and satisfaction of children/young people and their family is measured. [A]
The UK Ophthalmology Alliance	Children/young people are treated with dignity, kindness, compassion, courtesy, respect, understanding and honesty. [B]
The Royal College of Ophthalmologists	Parents and young people are routinely supplied with information in an accessible format on their diagnosis, treatment and medication. [A]
The UK Ophthalmology Alliance	A low vision leaflet (LVL), Referral of Vision Impairment (RVI) and Certificate of Vision Impairment (CVI) is offered as soon as children/young people are eligible. [B]
The UK Ophthalmology Alliance	Children/young people with vision impairment are referred to the local authority special education sensory impairment service as soon as sight impairment is identified, with the correct consent, to enable early intervention and support. [B]
The UK Ophthalmology Alliance	Children/young people are told how to seek advice and care in and out of hours, including for urgent problems, and should be able to make contact successfully. [B]
The UK Ophthalmology Alliance	Children/young people are advised where to find reliable high-quality information and support after appointments or consultations (e.g. from national or local support groups and voluntary organisations). [B]

Your notes

The eye care support pathway for children and young people with a vision impairment

Stage 3:
Support after diagnosis

Stage 3: Support after diagnosis

This section of the eye care support pathway begins when the child or young person is referred to local authority vision impairment support services. It looks at the assessment process and support families can expect to receive. It also outlines the registration and support process for receiving social care. Registration is one of the ways a Local Authority will become aware of a child's vision impairment and the need to assess them for support. It is optional and children do not need to be registered to receive support. However, registration may include benefits such as discounts on bus and rail travel, a blue badge, or a reduction in the cost of a TV licence. It may also help in a claim for welfare benefits.

This section can be considered alongside the 'Curriculum Framework for Children and Young People with Vision impairment' (CFVI), which supports children and young people to access equal opportunities in education, health and social care, as well guidance from Guide Dogs on 'Reasonable Adjustments in Schools'.

This stage has three parts:

Part 1: The eye care support pathway

Part 2: Support requirements

Part 3: The standards and guidance

For this stage, the pathway is split into two sections, which can occur at the same time:

Section 1: Support with education and local authority services

Section 2: Support with registration and social care.

▼ **Part 1:** The eye care support pathway
Section 1: Support with education and local authority services

1	Within five working days of diagnosis, they should be referred to the local authority sensory support team by an eye-care practitioner, such as an ophthalmologist, orthoptist, or hospital optometrist, to initiate support from a variety of services including from 'Qualified Habilitation Specialists' (RQHS) and 'Qualified Teachers of children and young people with a Vision Impairment' (QTVI), if not already receiving this support.
2	Within three working weeks, it is expected that the family support needs are assessed by the local authority sensory support team, who will signpost or refer the family to community groups and local and national charities, as needed.
3	Support, aids, training and educational adjustments will be assessed and reported on by a QTVI and RQHS in line with the Curriculum Framework and schools' legal requirements to provide 'reasonable adjustments' (see guidance above). They may be given an Education, Health and Care Plan (EHCP).
4	If appropriate, they will be referred to a low vision clinic, if they have not already, which may be based within a hospital or community setting. This referral may be made by a QTVI, RQHS, ECLO, hospital optometrist, or the clinical team at the hospital.

5	There will be ongoing engagement and joint working between education, local authority services, local optical practices, low vision practitioners and charity support services, as needed.

▼ **Part 1:** Eye Care Support Pathway

Section 2: Support with registration and social care

1	The child or young person and family are given information on registration and social care. This may be through their QTVI, but parents should receive a phone call from social services about registration.
2	If the child, young person or family chooses to register as sight impaired, they will be given the option to do so by the Local Authority once the Local Authority has received the CVI.
3	Upon opting to register, the child, young person and family will receive evidence of this registration as a certificate, either physically or digitally, sent directly to the family.
4	Within two weeks of registering, families should be given the option for assessment to see if they qualify for support from the local authority social care team. Assessment is not dependent on registration.
5	The local authority social care support team will assist with disability benefits, if needed, and can signpost or refer to other organisations and local and national charities that can support with welfare benefits and emotional wellbeing support, if needed.

▼ **Part 2:** Support requirements

Being eligible for a Certificate of Vision Impairment (CVI)	
The journey	• I understand that both certification and registration are optional processes, and what it means if I choose not to register. • I understand the process of certification. • I understand the process of registration and what benefits registration might have for me/my child. • I understand the process to get support if I/my child chooses not to be certified or registered.
The eye condition	• I am confident that the eye condition has been accurately reflected on my/my child's CVI.
Getting support	• I understand what I am entitled to once I have/my child has a CVI. • I feel that practical and emotional family support needs have been considered in my/my child's care

Waiting for engagement with my Local Authority	
The journey	• I understand I/my child may have a visit and assessment from a QTVI, and, if necessary, a RQHS.
The eye condition	• I have been given appropriate eye condition information from the local authority or QTVI. • I know how to manage the condition while I wait for support.
Getting support	• I know who to contact if I have questions or require immediate or ongoing support.

Working with habilitation and education specialists	
The journey	• I understand what professionals are involved in my/my child's care and why. • I have been assessed by a QTVI and RQHS and have received a report with recommendations on how to meet my/my child's need.
The eye condition	• I understand how support from a QTVI and RQHS contributes to care, education learning and development. • I feel confident managing the eye condition on an ongoing basis. • I feel confident in the support I need and where this will come from. • I have been provided with any adaptations I/my child may need to enable me/my child to manage the eye condition.
Getting support	• I/my child has been provided with practical and emotional support, aids, training and educational adjustments as needed. • I feel informed about the Curriculum Framework and how it will be used to support me/my child. • I understand how the support I am receiving interacts with any other support and pathways being followed for any additional conditions I/my child may have.

▼ Part 3: The standards and guidance

Standard/guidance source	Detail
NatSIP	In consultation with parents, children/young people will usually have their needs assessed by a QTVI within three working weeks of notification of a diagnosis. [D]
NatSIP	Education providers are given a clear written and verbal explanation of the QTVI assessment and what it means for the child/young person's strengths and needs, and the steps they will have to take to ensure the child or young person has access to teaching and learning and makes progress. [D]

Standard/guidance source continued…	Detail continued…
NatSIP	Parents are given the opportunity to become fully involved in QTVI assessments and articulate the needs of their child. [D]
The UK Ophthalmology Alliance	Access to support services are not driven by clinical limits and certification alone, but also by social, emotional, psychological, occupational and educational needs. [B]
The Curriculum Framework	Children/young people are confident that they can have an influence and impact on the decisions that are made regarding their education and life. [F]
The UK Ophthalmology Alliance	Low vision and habilitation services should provide support early to prevent loss of skills, confidence and motivation, and be ongoing to respond to changes in circumstances. [B]
Habilitation VI UK	Habilitation services need to enable and encourage children/young people and their families to be as fully involved in the planning, implementation, and review process of the habilitation training programme. [G]

Your notes

The eye care support pathway for children and young people with a vision impairment

Stage 4:
Living well with a vision impairment

Stage 4: Living well with a vision impairment

This is the final section of the eye care support pathway and covers the widest range of services. It outlines how a child or young person will be supported to live independently and well with their eye condition and with any wider emotional, wellbeing and physical health conditions they may have.

It also outlines the process for transitioning from children and young people clinical and social care services to adult services. Finally, it sets out what support to expect when children and young people transition between the different stages of education, from early years through to further or higher education.

This stage has three parts:

Part 1: The eye care support pathway

Part 2: Support requirements

Part 3: The standards and guidance

For this stage, the pathway is split into five sections. Each of these sections may overlap or occur at the same time:

Section 1: Eye care
Section 2: Other health conditions
Section 3: Education transitions
Section 4: Transition to adult clinical services
Section 5: Transition to adult social care services.

▼ Part 1: The Eye Care Support Pathway
Section 1: Eye care

1	If needed, the eye condition will be monitored on an ongoing basis. This may take place alongside primary eye care in your local optical practice, such as regular sight testing.
2	If the child, young person or parent/carer notices an EXPECTED change in vision that cannot be corrected by primary eye care, their hospital optometrist or ophthalmologist, the eye-care professional will refer them to the appropriate follow-up care, such as an appointment with the low vision clinic.
3	If the child, young person or parent/carer notices an UNEXPECTED change in vision that cannot be corrected by primary eye care or their optometrist, they will return to an ophthalmologist for assessment, either directly or through a referral from the eye-care professional.
4	The child or young person will be signposted or referred to community groups and local and national charities, as needed, including emotional wellbeing support, based on their emerging needs.

Part 1: The Eye Care Support Pathway
Section 2: Other health conditions

1. The child or young person's physical health, emotional wellbeing and any learning disabilities are monitored on an ongoing basis.
2. The child or young person may be referred to speech and language therapy or support from other related specialist professionals to support with wider development needs.
3. The child or young person will be signposted or referred to community groups and local and national charities as needed, including emotional wellbeing support, based on the emerging needs.

Part 1: The Eye Care Support Pathway
Section 3: Education transitions

1. When the child or young person is preparing to move from/to early years > primary > secondary school > further education and/or higher education, or there is a change to the eye or health condition, their educational and habilitation needs will be reviewed.
2. They will have an assessment of needs through a QTVI and RQHS before the transition to the new education setting.
3. Alongside this, there will be ongoing engagement with community groups and local and national charities, as needed.

Part 1: The Eye Care Support Pathway
Section 4: Transition to adult clinical services

1. If under active hospital care, the young person will start the process of clinical transition to adult services, with the first transition planning meeting held by age 14. If the young person is not under active hospital care, no transition to adult clinical services is needed.
2. Annual transition planning review meetings will take place.
3. The young person will be provided with a named worker to coordinate care and support throughout their transition.
4. The young person, alongside their parent or guardian where appropriate, will meet practitioners from each adult service that they are moving to.

Part 1: The Eye Care Support Pathway
Section 5: Transition to adult social care services

1. The young person starts the process of social care/education transition to adult services, with the first transition planning meeting held from age 14.

2	The young person will be referred to the Adult Vision Rehabilitation Specialist team for additional mobility support.
3	Regular transition planning review meetings will take place with the young person as needed.
4	In high-need circumstances, they will be supported in registering for any additional benefits that they are entitled to by their QTVI. Otherwise, they will be signposted or referred to organisations that can support them with registration.
5	They will be referred to adult social care.
6	Access to employment support will be provided by local or national charities, which will be signposted or referred to by a QTVI.
7	If desired, the local RQHS team will assess the needs of the young person to understand what support will be needed as an adult.

▼ Part 2: Support requirements

Supporting physical health and emotional wellbeing throughout childhood and adolescence	
The journey	• I understand each stage of the pathway and who to contact at each stage if I need further help.
The eye condition	• I understand what to do if the eye condition or vision changes. • I know what signs indicate a change or deterioration in vision.
Getting support	• I know how to find support that is relevant to me/my child. • I know what to do to ensure there is minimal disruption to my/my child's care when moving to a different local authority area. • I know what signs indicate a need for emotional wellbeing support. • I know how to access relevant products to support vision impairment access e.g. long cane or specialist IT equipment

Support with education transitions	
The journey	• I understand what professionals are involved in the process of my/my child's education transition, why and when. • I understand what additional support is available during an education transition.
The eye condition	• I understand that additional clinical assessments may be necessary during education transitions. • I know who to contact if vision or confidence changes post-transition.
Getting support	• I know what support and care to expect after each transition.

Support with clinical transition to adult services	
The journey	• I understand what steps may be involved in the process of transition to adulthood. • I am confident that my/my child's transition plans are regularly reviewed ahead of transition to adult services.
The eye condition	• I understand who to contact if vision changes post-transition.
Getting support	• I understand the level of support that I am/my child is entitled to in adult services. • I feel/my child feels emotionally prepared for care and support in adult services. • I understand how the support I am receiving interacts with any other support and pathways being followed for any additional conditions I/my child may have.

▼ Part 3: The standards and guidance

Standard/ guidance source	**Detail**
NatSIP	The education sensory support service puts transition arrangements in place from age 14. This should include assessing the young person's need for support to help overcome potential barriers, providing information on options, relevant work experience, full student engagement, transition visits and liaison with the future education setting or employer. [D]
NICE	Young people moving from children's to adults' services meet a practitioner from each adults' service before they transfer. [H]
Habilitation VI UK	The future habilitation needs of children/young people are included in transition planning meetings or annual review meetings from age 14-18. [G]
NICE	Young people start planning their transition with health and social care services by age 13-14 (or immediately if they enter children's services after age 14) and have annual meetings to review transition planning. [H]
NatSIP	Prior to a school or college transfer, the new school or college understands the child/young person's needs and how to ensure a successful transition. [D]
NICE	Young people have a named worker to coordinate care and support before, during and after transition to adult health and social care services. [H]
Habilitation VI UK	Children and young people are prepared for their lives after compulsory education and empowered to make decisions on their future. [G]

Your notes

Glossary

- **Certificate of Vision Impairment (CVI):** A document issued by an ophthalmologist certifying whether someone is sight impaired or severely sight impaired.

- **Eye Care Liaison Officer (ECLO)/Family Liaison Officer:** Specialist support worker who acts as a bridge between health, education and social services to support the wellbeing of patients in eye clinics.

- **Eye-care practitioner:** An Ophthalmologist, Orthoptist, Optometrist or Optician.

- **Dispensing Opticians:** An eye care specialist who supports in providing corrective glasses and lenses and are regulated to work with children for paediatric low vision and support.

- **General Practitioner (GP):** Doctors who treat all common medical conditions and refer patients to hospitals and other medical services for urgent and specialist treatment.

- **Habilitation:** Habilitation is the teaching of early movement and orientation and mobility skills, including body awareness, spatial awareness, and for some long cane training or other strategies to facilitate independent travel. Habilitation also includes a wide range of independent living skills.

- **Healthcare professional (HCP):** Any medical practitioner involved in giving medical advice and care.

- **Local Authority Sensory Support Team:** Specialist local authority team that provides children, young people and their families with information, advice, and support for their child's vision impairment. This may include QTVIs, RQHS, and specialist Teaching Assistants.

- **Local optical practice:** An optometric practice where sight tests are provided, such as a typical 'high-street opticians'.

- **Low vision practitioner:** An eye-care practitioner such as an Optometrist, Orthoptist, Dispensing Optician or Ophthalmic nurse who has specialised in low vision care.

- **Ophthalmologist:** Doctors trained in diagnosis and treating (including surgery) conditions and injuries that cause vision impairment.

- **Orthoptist:** Eye care practitioners/allied health professionals specialising in binocular function, including ocular motility, developmental and binocular vision disorders.

- **Optometrist:** Eye care practitioners specialising in eye health and the visual system and in glasses and contact lens corrections.

- **Primary eye care:** Eye care at the 'first point of contact', such as sight tests and the provision of glasses. This will likely take place at a local optical practice, such as a high street optometric practice.

- **Qualified Teacher of Children and Young People with a Vision Impairment (QTVI):** Qualified practitioners who provide day-to-day support for development and access to the curriculum for children and young people with a vision impairment.

- **Registered Qualified Habilitation Specialist (RQHS):** Qualified practitioners who work with children and young people (0-25 years) with a visual impairment. They can help children develop a broad range of skills, including early years development, independent life skills and moving around (orientation & mobility).

- **Special Educational Needs Coordinator (SENCO/SENDCO):** Qualified teacher responsible for supporting children and young people with special educational needs.

- **Vision impairment:** Sight loss in both eyes that cannot be fully corrected using prescription glasses or contact lenses.

- **Vision Rehabilitation Specialist:** Professionals who are qualified to support visually impaired adults to enable and empower them to live independently. Support is varied and can include delivering training and coaching to develop the life skills needed to live independently, communicate effectively and travel safely.

Standards and guidance – references

[A] The Royal College of Ophthalmologists – Care and Services for Children and Young People: Quality Standard Self-Assessment Tool

[B] The UK Ophthalmology Alliance: Patient Standard for Ophthalmology

[C] The Royal College of Ophthalmologists: Ophthalmic Services for Children

[D] NatSIP: Quality Standards for Sensory Support Services

[E] The College of Optometrists: Guidance for Professional Practice: Examining younger children

[F] Curriculum Framework for Children and Young People with Vision Impairment (CFVI)

[G] Habilitation VI UK: Habilitation Quality Standards - 2nd edition

[H] NICE: Quality Standard: Transition from children to adults' services

Further support

You may find further support from the following organisations:

The Association of British Dispensing Opticians

The Association of British Dispensing Opticians (ABDO) is the professional body for dispensing opticians – working for dispensing opticians and advancing the profession in the UK and worldwide. Dispensing opticians are healthcare professionals registered with the statutory regulator for the optical professions, the General Optical Council. Dispensing opticians are specialists in paediatric eyewear and qualified in low vision and are also able to gain a further qualification that enables them to register as contact lens opticians.
www.abdo.org.uk

BAME Vision

BAME Vision are on a mission to address the inequalities experienced by blind and partially sighted people and those at risk of sight loss from ethnically diverse communities. We want to ensure everyone from ethnic communities can make informed choices about their care and wellbeing relating to their vision. We aim to break down barriers and work in collaboration to embed an inclusive approach, as well as support vision impaired people from diverse communities and break down stigma.
www.bamevision.org

BIOS

The British and Irish Orthoptic Society (BIOS) is the professional body for Orthoptists, healthcare professionals specialising in the diagnosis and management of binocular vision disorders, visual impairment, and ocular motility dysfunction. Specialist low vision orthoptists advise on children’s vision, educational support, and assistive technology to bridge healthcare and education for visually impaired children.
www.orthoptics.org.uk

Clinical Council for Eye Health Commissioning

The Clinical Council for Eye Health Commissioning (CCEHC) is an independent advisory body, representing the leading clinical professions and charity organisations in the eye-care sector in England. It works with NHS England to improve eye health outcomes and access and promote high quality accessible eye health services that address local health inequalities.
college-optometrists.org/clinical-council-for-eye-health-commissioning

Contact: For families with disabled children

Contact's vision is that families with disabled children feel valued and are strong, confident and able to make the decisions that are right for them. The charity provides information, advice and support for families with disabled children as well as support and training for practitioners.
www.contact.org.uk

The College of Optometrists

The College of Optometrists is the professional body for optometry. It qualifies the profession and delivers the guidance and training to ensure optometrists provide the best possible care. We promote excellence through the College's affixes, by building the evidence base for optometry, and raising awareness of the profession with the public, commissioners, and health care professionals.
www.college-optometrists.org

Esme's Umbrella

Esme's Umbrella offers support for all adults and children who live with Charles Bonnet Syndrome (CBS), together with their families, caregivers, guardians and teachers. The charity raises awareness of CBS and sourcing funding for vital research.
www.charlesbonnetsyndrome.uk

FODO

FODO is the leading national association for eye care providers working in primary and community care settings. We are committed to high quality eye care for all. Each year our members provide over 18 million eye examinations and offer a wide range of other eye care services across the UK.
www.fodo.com

Guide Dogs

Guide Dogs provides a wide range of services with and without dogs, to support children and adults with a vision impairment, and their families. Their expert staff, dedicated volunteers and life-changing dogs help people with sight loss live actively, independently, and well.
www.guidedogs.org.uk

Glaucoma UK

Glaucoma UK is a national charity providing information and support to people with glaucoma. Advice is available to parents and carers of children who are living with the disease via the charity's helpline service.
www.glaucoma.uk

Habilitation VI UK

The professional body membership organisation specialising in habilitation services, empowering children and young people with vision impairment to develop independence, confidence, and essential life skills.
www.habilitationviuk.org.uk

LOCSU

LOCSU is the Local Optical Committee Support Unit, supporting Local Optical Committees (LOCs) in England across a range of activities relating to primary eye care. Underpinning our work is a determination to make it easier for LOCs to maximise opportunities and improve eyecare in their area. We do this by providing practical support to LOCs in pathway development, governance and compliance, training and by liaising with and influencing commissioners and wider primary care.
www.locsu.co.uk

LOOK

Empowering visually impaired young people and their families through a network of dedicated support services and resources.
www.look-uk.org

Macular Society

The Macular Society is the leading charity in the UK supporting people with macular disease, the biggest cause of sight loss in the developed world. The charity provides practical and emotional support to help those living with the condition and funds medical research to help find a cure.
www.macularsociety.org

Mind

A national mental health charity, offering support, advice and information relating to mental health and wellbeing. Mind offers a range of services including helplines, online resources and local support groups.
www.mind.org.uk

NatSIP (National Sensory Impairment Partnership)

NatSIP (National Sensory Impairment Partnership)
The National Sensory Impairment Partnership is a unique national partnership of professionals and the main voluntary and professional organisations working across the sensory impairment sector to improve outcomes for children and young people with SI (deafness, multi-sensory and vision impairment) and their families..
www.natsip.org.uk

Retina UK

Retina UK is a national charity offering information and support to people affected by inherited sight loss. This includes practical and emotional support for parents and carers via their Helplines and Parent Peer Support Group. Their webpages and Frequently Asked Questions provide details about the conditions and helpful information when planning hospital visits
www.retinauk.org.uk

The Royal College of Ophthalmologists

The Royal College of Ophthalmologists is the professional body for medically qualified eye doctors. It educates and supports a community of practitioners, sets clinical standards, promotes research, champions the profession and influences national eye care policy to ensure excellence in the prevention, treatment and management of eye diseases.
www.rcophth.ac.uk

Royal National Institute of Blind People (RNIB)

RNIB offers practical and emotional support to blind and partially sighted people, their families and carers. They raise awareness of the experiences of blind and partially sighted people and campaign for change to make society more accessible for all.
www.rnib.org.uk

RSBC

Providing children and young people with a vision impairment and their families with a combination of support, education, and development opportunities to help them build resilience and the skills they will need to navigate their own futures.
www.rsbc.org.uk

RWPN

The Rehabilitation Workers Professional Network is dedicated to supporting and advancing the work of rehabilitation and dual-qualified workers rehabilitation/habilitation specialists. They hold the professional accredited register for Vision Rehabilitation and dual-qualified specialists. RWPN set out and maintain professional standards for the workforce and promote the value of vision rehabilitation for blind and partially sighted people, seeking to strengthen professional identity and influence across the UK, and provide a platform for networking, development, advocacy, and leadership.
www.rwpn.org.uk

SeeAbility

SeeAbility specialises in supporting people who have learning disabilities or autism, who may also have sight loss. Support includes specialist housing, as well as information, advice and working to improve access to eye care services and support for children and adults with learning disabilities and/or autism.
www.seeability.org/eye-care

Thomas Pocklington Trust (TPT)

TPT believes blind and partially sighted students should have the opportunity to thrive in their education. They work to improve outcomes and address barriers faced by many students. They provide information and support to children and young people, students, parents and carers and professional on primary, secondary, further and higher education.
www.pocklington.org.uk

VICTA

VICTA is a national charity that empowers children and young adults from 0 to 29 who are blind or partially sighted. They offer a range of in-person activities, online challenges and virtual events for student engagement, social and employability skills development, family support and parent services.
www.victa.org.uk

VIEW (Vision Impairment Education and Workforce Development)

VIEW is the professional association for the vision impairment education workforce that supports children and young people with vision impairment across a range of mainstream and specialist settings. VIEW works to safeguard standards of provision, represent the views of the vision impairment workforce and advocate for the educational needs of children and young people with vision impairment.
www.viewweb.org.uk

Visionary

Visionary is the UK's membership organisation for local sight loss charities across the UK. Local charities provide community-based services, including support for children, young people and families affected by visual impairment.
www.visionary.org.uk

Acknowledgements

We would like to thank all those from the eye care sector that contributed to the development of this resource. Each stage of the pathway was based on interviews and workshops with:

- Parents of children and young people with a vision impairment
- Consultant Ophthalmologists
- Local authority sensory support professionals
- Local authority commissioners
- Professional/trade body professionals
- VI charity sector representatives
- Registered Qualified Habilitation Specialists (RQHS)
- Qualified Teachers of Children and Young People with Vision Impairment (QTVIs)

We held additional workshops with young people and parents to develop the support requirements and would like to thank them for their time and enthusiasm.

We are grateful to the Working Group made up of VI sector professionals, healthcare professionals and those with lived experience, who advised Guide Dogs throughout this project. Their input was invaluable, and we thank them for their efforts.

For further information about the eye care support pathway please contact us at:

CYPEyeCareSupportPathway@guidedogs.org.uk

www.guidedogs.org.uk

The Guide Dogs for the Blind Association is a registered
charity in England and Wales (209617), Scotland (SC038979)
and Isle of Man (1334). D101 07/25