Low Vision, Habilitation and Rehabilitation Framework for Adults and Children

June 2017
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**Target Audience:** CCG Clinical Leaders, CCG Accountable Officers, CCG Directors of Commissioning, Directors of Adult & Social Services, Directors of Children’s Services, Local Authority services, Voluntary and Charity organisations, NHS England, Public Health England and Service Users.

**Date of Review:** July 2019
1 Introduction

This resource has been developed using the best evidence available (ophthalmic research literature, established guidance, case studies and service audit) and relates solely to commissioning of low vision, habilitation and rehabilitation services (LVHRS) in England. The framework is appropriate for the alignment of commissioning between health, social care and education funded services for children and adults, including those unable to leave home unaccompanied because of physical or mental illness or disability, but may be useful for services provided by charities and voluntary services.

It supports four of the six key priorities of the England Vision Strategy.¹

- Detecting eye conditions early, especially in seldom heard groups.
- Promoting a consistent strategy for eye care commissioning.
- Improving the Certification process – making sure people who are eligible actually get certified and registered and that relevant data flows through the whole eye health and sight loss pathway.
- Early intervention to ensure practical and emotional support post diagnosis (for example, an eye clinic liaison officer available in every eye department).
- Habilitation and rehabilitation available on a free and timely basis for as long as needed to learn or relearn key life skills including mobility.
- Development of peer support and self-help groups in every community for adults, children and families to provide voluntary sector support for independent living and to lobby for inclusive local public services.

…and supports the ‘Seeing it my way’² outcomes (Appendix A). This UK Vision Strategy initiative is designed to ensure that every sight impaired and severely sight impaired person, regardless of age, ethnicity, extent of sight loss, other disabilities, or location across the UK, has access to the same range of information and support.

Low vision has a significant impact on a person’s independence and quality of life. For example, older people with low vision are more likely to fall or suffer from social isolation and depression than their sighted peers. It is therefore important for commissioners to understand the value placed on these services by those whose sight has been affected.

LVHRS often lack data to support the need for service and commissioning decisions, and frequently lack dedicated budgets. In developing the framework, the focus has been on ensuring quality, reducing service variation, improving equity of access, and enhancing outcomes through timely intervention. Like the primary eye care and community ophthalmology frameworks³, the emphasis is on promoting integration across primary and community care, hospital eye service (HES), education, social care, voluntary services, and stroke, rehabilitation and falls teams to deliver better outcomes and eliminate duplication and waste of resources. Vision rehabilitation is crucial to ensuring that someone who loses their sight remains as independent as possible. Independent research commissioned by RNIB as part of a Department of Health funded project has identified that good vision rehabilitation also avoids significant health and social care costs; the costs avoided are more than three times the cost of delivering the service.⁴

Certification of vision impairment and subsequent registration allows access to assessments by habilitation and rehabilitation services. Greater flexibility is essential so that users can access
reassessments as their vision changes. It should be noted that people who have reduced/low vision but do not meet the criteria for certification do need to be considered for service planning.

Children with low vision have different needs from adults since reduced visual input presents a major obstacle to the acquisition and development of fundamental developmental skills in early and later childhood. Children and young people are at risk of poor outcomes and successful transition to independent adulthood is dependent on having good independent learning, mobility, everyday living and social communication skills (the ‘additional curriculum’). Children with low vision therefore require a comprehensive low vision service which looks at emotional wellbeing as well as the skills needed to use various devices and teach different ways of doing everyday tasks. Early intervention is crucial and it is important that clinical services work with education and habilitation services, as set out in the Children and Families Act 2014 and the Special Educational Needs and Disability (SEND) Code of Practice 2015.5

Definitions of low vision, low vision aids, low vision service and low vision training can be found in Appendix B.

2 Case for change

The current system of LVHRS is fragmented and more joined up commissioning is needed to ensure consistency of services for users, and the avoidance of a post code lottery. In some areas, services do not exist and the population need has not been assessed.

The overall aim of a LVHRS is access to habilitation and rehabilitation supported by the provision of appropriate equipment and expertise to improve quality of life.

Additional aims are listed below, a few of which may not be relevant in some areas.

1. Personalised care that follows service users and meets their needs and risks.
2. Provision of safe, timely and effective care by appropriately trained and competent professionals.
3. Provision of aids on loan, information on technology, signposting, mobility training appropriate to the individual.
4. Ongoing development of the current service and future workforce planning.
5. Efficient pathways to make best use of available resources and skills.
6. Embedding audit and governance structures into the service.
7. Provision of LVHRS in a setting closer to home, study or work.
8. Integrated, multi-disciplinary pathways including across primary and hospital care, social services, education and voluntary sector.
10. Equitable access to ensure users are not denied LVHRS or do not have access to these services; for example, those who are confined to their homes or residential establishments, non-English speakers, asylum seekers and other seldom heard groups.

In many areas, there is no accessible community low vision service, and the referral route can involve the optometrist referring to the GP, and the GP referring to the HES. Most HES departments provide low vision clinics supported by an eye clinic liaison officer (ECLO). In some areas, low vision services are separately commissioned and delivered outside the HES. ECLOs are key in linking patients to services and helping patients understand the impact of their diagnosis.
They provide emotional and practical support and importantly, have the time to dedicate to patients following consultation.

An ECLO service is an essential part of the eye health and sight loss pathway and therefore should be included in contracts and service specifications.

LVHRS should be seamlessly incorporated into the eye care and sight loss pathways and not as an afterthought. Many adult patients access low vision assessments when sight loss has occurred and further treatment is no longer effective. Earlier anticipated access to low vision services could lead to better outcomes, when there is some useful vision present.

The prevalence of low vision in children is far lower than in adults and the population is not evenly distributed. The SEND Code of Practice recognises joint commissioning between local authorities as an effective way of meeting the needs of children with highly specialised and/or low incidence needs such as vision impairment. Children access low vision assessments in a variety of ways such as education and habilitation services.

Whatever the route, there needs to be clear signposting to services.

Increasing demand on eye health services due to the ageing population and the availability of new treatments are creating capacity bottlenecks, especially in the HES in relation to AMD, diabetic eye disease and glaucoma. This will also increase demand and waiting times for low vision clinics. There is variation in the waiting times for initial low vision appointments/assessments and follow up appointments with some clinics having very long waits with equally long waits for habilitation and rehabilitation assessments. In some areas, low vision follow-up appointments are not offered and this impacts on measuring outcomes.

A LVHRS involves understanding and ascertaining patients’ needs and requirements as well as assessing their visual capabilities to facilitate a program of visual rehabilitation which may involve the dispensing of an appropriate device. Effectively, the tariff paid needs to fund all aspects of this care. All aspects of such care are needed for integrated care, irrespective of who delivers the care or where it is delivered. In the HES, payment for the low vision assessment is based on an outpatient tariff structure with the tariff being used to pay for both professional time and the device. Often, there is no dedicated funding of the low vision budget, and low vision services and appliances are cross-subsidised from the HES tariff payment, which is usually designed to only cover the clinical consultation element. It is therefore recommended that commissioners use the local tariff variation arrangements to agree a dedicated low vision budget to ensure sustainability of the service. Pooling buying power in some areas may enable better value purchase of appliances, more advanced equipment and timely supply. Commissioners may also wish to consider joint funding arrangements.

Key outcomes from the LVHRS framework are:

- Appropriate access to services.
- Address inequality of current service outcomes leading to a good service user experience.
- Better data to inform commissioning and delivery plans.
- Services delivered consistently across an area and integrated across pathways, resulting in less duplication and waste.
The drive for more healthcare in the community is in line with the NHS planning guidance and embedded throughout the NHS 5YFV. Key objectives in reorganising services are to achieve better integration, efficiencies and the better management of patient flows as well as freeing up capacity in the HES.

**Patient centred pathways and care**

The traditional separation between primary care, community services, hospitals, education and social care - largely unaltered since the foundation of the NHS - can be a barrier to the personalised and coordinated health services patients need unless there is proper planning, cross-referral, signposting and inter-professional communication. All services need to provide users with improved access and clearly understandable information.

**Population size**

The size of population served by the LVHRS in England will depend on a number of geographical and demographic factors. However, there may be significant financial and operational advantages for groups of neighbouring CCGs and local authorities to collaborate and commission more integrated services to meet the needs of a much larger population while minimising procurement costs. It is acknowledged that HES catchment areas and CCG and local authority boundaries are not always the same and therefore systems need to ensure there is equity in services.

Sustainability and Transformation Partnerships (STP) provide the opportunity for groups of CCGs and local authorities to work with providers to agree consistent pathways to develop truly transformed and sustainable services.

### 3. Mapping current services / pathways

Before commissioning a LVHRS, an eye health needs assessment should be completed to provide a baseline and establish if there are specific local priorities that need to be addressed. There are some key questions to consider:

- Have you engaged patients, service users and the wider public to understand the health inequalities arising in patients with poor vision?
- Have you consulted current primary, secondary care, local authority providers and voluntary organisations?
- Have you consulted with your Local Eye Health Network?
- How is care currently delivered, by whom and where?
- What is the level of activity/demand that needs to be delivered?
- Have you identified which patient groups will be included in the service specification?
- Are there health professionals ready and willing to develop their skills and take on a wider role?

Low vision service provision varies greatly across the UK.

**Wales**

While some low vision aids are available privately in some optical practices; in Wales, access to funded low vision services is widely available. In some areas, voluntary and charity organisations provide aids. Due to long waiting times and poor access to existing low vision services, the Welsh Assembly Government chose to develop primary care based low vision services throughout Wales. The NHS funded Low Vision Service Wales now operates out of over 185 optometric practices.
Multidisciplinary working is achieved by optometrists and dispensing opticians linking with community and hospital based professionals and organisations.

Scotland

A 2017 review of low vision service provision in Scotland\(^\text{11}\) identified a lack of uniformity across Scotland. There was variability across service types. This included inequitable access, both in terms of geographical location and waiting times. The report cited evidence of an effective method of service delivery from Wales and called for policy makers to develop an evidence-based solution to improve the access and equality of services.

Northern Ireland

An integrated models/pathways task group has been set up to review a range of services for long term eye conditions to enhance access and improve outcomes. This includes low vision services.

4 Low vision, habilitation and rehabilitation service team

The LVHRS team could include:

<table>
<thead>
<tr>
<th>Service</th>
<th>Professional / Dispensing Optician</th>
<th>Role</th>
</tr>
</thead>
<tbody>
<tr>
<td>Low Vision Primary care</td>
<td>Optometrist / Dispensing Optician</td>
<td>NHS sight test / clinical assessment</td>
</tr>
<tr>
<td>Hospital</td>
<td>Optometrist (access to paediatric</td>
<td>Community low vision assessment</td>
</tr>
<tr>
<td></td>
<td>ophthalmology and paediatrician)</td>
<td>Provision of aids and guidance</td>
</tr>
<tr>
<td>Low Vision</td>
<td>Ophthalmologist (access to</td>
<td>Clinical assessment / certificate of vision impairment (CVI)</td>
</tr>
<tr>
<td>Support</td>
<td>paediatric ophthalmology and</td>
<td></td>
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<tr>
<td></td>
<td>paediatrician)</td>
<td></td>
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<tr>
<td></td>
<td>Optometrist / Dispensing Optician / Orthoptist / Ophthalmic Nurse / Allied Health Professional (AHP) in ophthalmology</td>
<td>Clinical and low vision assessment Provision of aids and guidance Liaison, support and signposting</td>
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<td></td>
<td>ECLO Eye clinic volunteers</td>
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<td></td>
<td>Emotional support councillors</td>
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<tr>
<td>Rehabilitation</td>
<td>Rehabilitation Officer for Visually Impaired People (ROVI)*</td>
<td>Assessment and training</td>
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<td></td>
<td>Emotional support councillors</td>
<td>Independent living skills</td>
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<tr>
<td></td>
<td>Sight loss advisors within voluntary / charity sector linked to adult sight loss pathway</td>
<td></td>
</tr>
<tr>
<td>Habilitation / Education (Children and young people)</td>
<td>Qualified teachers of children and young people with vision impairment</td>
<td>Assessment, professional advice and direct support to ensure children’s access to the additional curriculum</td>
</tr>
<tr>
<td></td>
<td>Registered Qualified Habilitation Specialist (RQHS) or mobility teacher / habilitation worker</td>
<td>Assessment and training</td>
</tr>
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</table>
5 The adult UK eye health and sight loss pathway

The adult UK eye health and sight loss pathway\textsuperscript{12} represents the ideal process map to underpin the universal quality and outcomes framework for severely sight impaired and sight impaired people. Although the map suggests a linear process, people should be able to move back and forth between services.

The pathway diagram only appears linear as a way of representing it easily. Actual practice will vary and flexibility is vital; people may join the pathway at different points and may be referred to an earlier stage at any point.

For example, optometrists or opticians who are qualified to provide low vision assessments may have to refer the patient if they are not commissioned to provide that service.

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N.B. Children with low vision require referral to the LVHRS as soon as possible.
6 Competencies required for service components

Section 4 lists the range of professionals involved in LVHRS and Section 5 describes their involvement in the Adult UK Eye Health and Sight Loss Pathway.

Those working in LVHRS should be qualified or be undergoing appropriate training for the role.

The skills required vary along the pathway because of the diverse workforce and commissioners may, for quality assurance purposes, seek evidence from providers of continuing professional development and revalidation of skills.

The roles and responsibilities in the processes of commissioning and provision of eye care need to be clear to ensure safe, effective care based on clinical, educational and social needs.

7 Clinical leadership and governance

Effective local clinical leadership is essential to support appropriate clinical governance and clinical accountability arrangements.

Governance arrangements should not only include having appropriate procedures to demonstrate information and financial governance, but also procedures for prospective evaluation of the design and delivery of new care pathways which show:

- Effective outcomes.
- More appropriate and effective patient management (for example, an ECLO can liaise with patients and colleagues in the community, HES and social services to assist in the development of patient focussed more joined-up pathways).
- Patient safety.
- Clinical audit.
- Competence of the workforce.
- Positive patient experiences.
- Appropriate infrastructure and administration (equipment, premises, ordering, etc.).

8 Defining performance measures and the need to evaluate outcomes

The VISION 2020 UK portfolio of eye health indicators has been endorsed by the Clinical Council for Eye Health Commissioning. These indicators are designed to review and monitor population eye health and wellbeing at a national and CCG level. Indicator 9 and 10 monitors the coverage of ECLOs and availability of low vision services.

The following documents are available promoting quality and good practice:

- Commissioning better eye care: adults with low vision.
- Quality Standards - Delivery of habilitation training (mobility and independent living skills) for children and young people with visual impairment.
- See, Plan and Provide: The state of vision rehabilitation support across England.
- RNIB 10 principles of good practice in vision rehabilitation.
Well defined key performance indicators (KPIs) and methods of measuring them are vital. Outcomes and associated measures will need to be developed but as an initial step, some KPIs and activity measures are listed below.

### Service performance / activity measures

<table>
<thead>
<tr>
<th>Performance / activity measures</th>
<th>Desired Outcome</th>
<th>Measure</th>
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<tbody>
<tr>
<td><strong>Low Vision Activity</strong></td>
<td>Collection of data</td>
<td>Number and source of referrals to the service Time to access service Waiting time for first low vision appointment Waiting time for low vision follow up appointment Number and source of referral for children and young people Full list of equipment including numbers given on loan to users</td>
</tr>
<tr>
<td><strong>Access</strong></td>
<td>Timely access to services Timely access to follow up Children</td>
<td></td>
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<tr>
<td><strong>Provision</strong></td>
<td>List of equipment</td>
<td></td>
</tr>
<tr>
<td><strong>Rehabilitation Activity</strong></td>
<td>Collection of data</td>
<td>Number of rehabilitation workers in or linked to the service Number of referrals received into rehabilitation Equipment used Waiting times from date of referral to first rehabilitation assessment Waiting time to repeat assessments if circumstances change</td>
</tr>
<tr>
<td><strong>Access</strong></td>
<td>Timely access to rehabilitation, services and equipment Emotional wellbeing outcomes, specific life goals for patients, education Timely access to specialist counselling / mental health services</td>
<td></td>
</tr>
<tr>
<td><strong>Habilitation (Children and young people)</strong></td>
<td>Collection of data on children and young people (CYP) Provision of a habilitation service in your area? Assessment of all CYP with low vision</td>
<td>Local determination Number in habilitation team Who provides service (education or social care) Number of uses of the service</td>
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Each provider should be required to audit and review their service regularly. They should work collaboratively with other providers to implement a continuous quality improvement approach.
Integrating the LVHRS with community, hospital and local authority services

Low vision services should be available in primary care, hospital eye service and voluntary sector settings, enabling patients to have choice, with primary care or a voluntary sector setting being more convenient for some, while others with regular appointments in the HES may be able to combine appointments, and use hospital transport. All providers need to be able to link easily with the local habilitation and rehabilitation services, the vision impairment education service and with other specialist services such as for children and people with learning disabilities.

While having choice of low vision services is important, patients must still receive the treatment and monitoring of their eye care they need to prevent further sight loss. This is to ensure that all appropriate medical interventions are being or have been employed to improve an individual’s eyesight (for example cataract extraction) and/or help to retain it (e.g., treatment for glaucoma).

Timely access to low vision support after hospital diagnosis is crucial. Similarly, regular sight tests or eye examinations should continue to detect change and ensure that spectacle prescriptions are optimal.

Duplication of effort may be minimised, and integration and outcomes maximised by alignment of budgets for low vision programmes between local organisations. This should include resources to cover future development plans for education and advanced care plans. This approach will support the common vision for integrated care from the service user’s perspective which is described as ‘my care is planned with people who work together to understand me and my carer(s), put me in control, co-ordinate and deliver services to achieve my best outcomes’.

To maximise integration, there should be:

- A single service specification.
- Agreement on whole system pathways for low vision to minimise duplication and streamlining processes.
- Low vision services working as seamlessly as possible with other services including primary care, community, HES, education, social care, voluntary and charity organisations, and stroke, learning disability, habilitation, rehabilitation and falls teams.
- Timely referral to low vision services from primary care, community ophthalmology or the voluntary sector supported by ECLOs.
- Agreement of a communication plan so that all practitioners and patients are engaged and informed of guidelines signposting users to key services.
- Agreement of a communication route for patients, carers and parents so they can contact the services directly, to discuss their personalised low vision care or an education health care plan (EHCP) in the case of children and young people.
- Effective sharing of data at every stage of the patient’s pathway to ensure good communication and secure interchange of relevant information between health, care and education professionals, and their patients, ideally provided by electronic patient records.
- Effective data collection and audit across the pathways to help identify patients who are lost to follow-up and enable those managing service provision to plan more effectively.
- Smooth transition between children’s and adult services to avoid patients getting lost in the system, especially in the 18 – 25 age group (Paediatric low vision provision may be only accessible in school with equipment shared with others, which then becomes unavailable in further education).
• Smooth transfer of services and information when patients move from one area to another.
• Clear information, advice and guidance provided to patients to allow them to understand what resources are available for them and how they might benefit.
• Access to local low vision support through local voluntary societies.

There should be closer working between primary care (GPs, community optometrists, dispensing opticians) and the rest of the LVRHS pathway. Referral to low vision services should be as easy as possible and allow for self-referral especially for those who have existing conditions and need a reassessment. Pathways need to include routes where patients can easily get back to ophthalmology where there is suspicion of change in pathology.

The GP has a key role for holding patient information and should be informed every time patient care is transferred from one setting to another.

LVHRS need to be included in the Local Digital Roadmaps to deliver 'Paper Free at the Point of Care' in line with the 5YFV and 'Personalised Health and Care 2020'.

10 Equality provision of the LVHRS

Services need to meet the legislation requirements under the Equality Act 2010. The law requires providers to make reasonable adjustments when seeing disabled people. NHS information must be provided in an accessible format.

All organisations that provide NHS care or adult social care are legally required to follow the Accessible Information Standard. The standard aims to make sure that people who have a disability, impairment or sensory loss are provided with information that they can easily read or understand and with support so they can communicate effectively with health and social care services.

This document is available in large print.
11 References


4) Effective Vision Rehabilitation can avoid significant costs to Health and Social Care: http://www.rnil.org.uk/rehabcostavoidance


7) The Royal College of Ophthalmologists: https://www.rcophth.ac.uk/2016/03/increasing-demand-on-hospital-eye-services-risks-patients-losing-vision/

8) NHS Five Year Forward View: https://www.england.nhs.uk/ourwork/futurenhs


17) 10 principles of good practice in vision rehabilitation: https://www.rnil.org.uk/sites/default/files/10%20principles%20of%20Good%20Practice%20in%20Vision%20Rehabilitation.pdf


A framework development group was established to review and advise on the content of the framework. This group met via webinar and face-to-face over a period of three months.

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</tbody>
</table>

Reference group

With special thanks to Fergus Macbeth - patient representative, Zoe Richmond - LOCSU lead, Barbara Ryan - Wales Optometry Postgraduate Education Centre, Rebecca John - Clinical lead for the Low Vision Service Wales, Rasmeet Chadha - Oxford Eye Hospital, Sue Keil - RNIB.
Appendix A. ‘Seeing it my way’ outcomes

All the outcomes are equal in value and are not listed in any order of priority.

1. That I understand my eye condition and the registration process.
2. That I have someone to talk to.
3. That I can look after myself, my health, my home and my family.
4. That I receive statutory benefits and information and support that I need.
5. That I can make the best use of the sight I have.
6. That I can access information making the most of the advantages that technology brings.
7. That I can get out and about.
8. That I have the tools, skills and confidence to communicate.
9. That I have equal access to education and lifelong learning.
10. That I can work and volunteer.

Regularly review the impact and quality of your services by asking blind and partially sighted people, their families and carers whether they think the ‘Seeing it my way’ outcomes are being delivered and what areas still need improvement.
Appendix B. Definitions

The following definitions have been adapted for this framework from the Low Vision Services Consensus Group (1999).\textsuperscript{21}

A person with low vision is one who has an impairment of visual function for whom full remediation is not possible by conventional spectacles, contact lenses or medical intervention and which causes restriction in that person’s everyday life.

Such a person’s level of functioning may be improved by providing low vision services including the use of low vision aids, environmental modification and/or training techniques. This definition includes, but is not limited to those who are registered as sight impaired or severely sight impaired.

A low vision service is a rehabilitative or habilitative process, which provides a range of services for people with low vision to enable them to make use of their eyesight to achieve maximum potential.

This is not just a technical process. The services should include:
- planning the rehabilitative process, setting goals and support in understanding the limitations involved.
- addressing psychological and emotional needs.
- providing information and advice.
- assessing the person’s visual function and providing aids and training.
- facilitating modification to the home, school and work environments.

The support needs to extend to the needs of carers, especially the family.

A low vision aid is any piece of equipment used by people with low vision to enhance their vision.

Such aids may be:
- optical including hand and stand magnifiers, illuminated magnifiers, telescopic lenses for both distance and near, and spectacle mounted magnifiers
- electronic such as closed-circuit television systems (CCTV’s), specialised computer adaptation, mobile phone and tablet applications
- non-optical such as lighting, typoscopes and large felt tip pens.

Low vision training is any individually tailored tuition in the use of vision or low vision aids.

Such training may include:
- training in the use of vision such as using discernible visual landmarks for orientation or adopting different eye movement techniques for locating objects or reading;
- training in the use of low vision aids such as how best to position and hold a hand magnifier, or use a writing frame and felt tip pen when writing
- training in the adaptation of the environment such as finding the best lighting or using colour contrast to help navigation.

Eye Clinic Liaison Officers (ECLOs) work closely with medical and nursing staff in the eye clinic, and the sensory team in social services. They provide those recently diagnosed with an eye condition with the practical and emotional support which they need to understand their diagnosis,
deal with their sight loss and maintain their independence. An important function is to signpost to other services in their area.

**Education Health Care Plans (EHCP)** are for children and young people aged up to 25 years 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.
The Clinical Council for Eye Health Commissioning (CCEHC) is the national clinical voice for eye health in England.

The CCEHC brings together the leading professional, patient and representative bodies involved in eye health, providing collective expertise to commissioners, providers, clinicians and policy-makers on the commissioning of eye health services, including social care and ophthalmic public health in England.

The CCEHC’s recommendations are provided in the best interest of patients, on the best evidence available and independent of any professional or commercial interests.

The CCEHC brings together the following organisations in the sector:

- Association of Directors of Adult Social Services
- Association of British Dispensing Opticians
- British and Irish Orthoptic Society
- College of Optometrists
- Faculty of Public Health
- International Glaucoma Association
- Macular Society
- Optical Confederation (including the Local Optical Committee Support Unit)
- Royal College of General Practitioners
- Royal College of Ophthalmologists
- Royal College of Nursing (ophthalmic section)
- Royal National Institute of Blind People
- VISION 2020UK