



OPHTHALMIC SERVICES FOR CHILDREN

1. Background

This document summarises the views of the Paediatric Subcommittee of the Royal College of Ophthalmologists regarding best practice and minimum standards in relation to health services for children with ophthalmic disorders, in keeping with the [RCOphth's Quality Standards / Indicators for Paediatric Ophthalmology](http://www.rcophth.ac.uk/page.asp?section=444§ionTitle=Quality+Standards). (<http://www.rcophth.ac.uk/page.asp?section=444§ionTitle=Quality+Standards>)

Ophthalmic disorders, as defined here, include eye disease, disorders of cerebral function affecting vision, and visual impairment. The Committee endorses the standards laid out in the National Service Framework for Children, Young People and Maternity Services: Change for Children – Every Child Matters¹ and in 'Healthy lives, Brighter futures' (http://www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH_094400)

The term children is used in this document to refer to individuals less than 12 years of age, and young people to refer to individuals between 12 and 16 years of age.

Despite the upcoming substantial changes in health service provision in the UK, the purpose of ophthalmic health services for children remains:

1. Primary prevention:

Preventing the occurrence of visually impairing disease through effective screening and treatment - e.g. screening of premature neonates for retinopathy of prematurity



Ophthalmic Services Guidance

2. Secondary prevention:

Reducing the visual impact of established disease - e.g. screening for vision impairment in 4-5 year old children followed by appropriate treatment

3. Tertiary prevention

Maximising function in individuals with permanent visual impairment - e.g. provision of low vision aids for children with congenital eye anomalies or habilitation/rehabilitation programmes.

2. Introduction

Consideration of the effects of ophthalmic disorders, and their treatment, on the child's general development and quality of life should be paramount. To deliver high quality services, it is essential to address the specific needs of children with ophthalmic disorders as well the needs of their families. The following issues shape these needs, which differ from those of adults:

A child's health encompasses their physical, emotional and social development. Visual loss in childhood can significantly impair progress in any of these dimensions². Equally, developmental delay will impact on a child's functional vision. Paediatric ophthalmic disorders and their management should be viewed in the broader context of general health and development – services should be child-centred.

Effective partnership between children/young people, their parents and health professionals is central to the successful management of all children with ophthalmic disorders, with, in many situations, the parents implementing the treatment, for example administration of eye drops or carrying out occlusion for amblyopia. The configuration and content of ophthalmic services should reflect the central role of individual parents (with their specific circumstances) in clinical-decision making.



Ophthalmic Services Guidance

Effective partnership depends on clear communication between parents, children and professionals. Health professionals should ensure that information about a child's ophthalmic disorder is presented in an understandable way and is supplemented by written information, including copies of clinic letters, where appropriate. Health professionals should communicate with each other and with education and social care professionals, as appropriate, to ensure the needs of the child are met.

Parents are usually effective as expert advocates for their children, although they may be constrained by their socio-economic, demographic or other personal circumstances³. Parental advocacy should be supported and encouraged through provision of information and social and emotional support, both in the context of the management of individual children as well as more broadly in relation to the planning of ophthalmic services for children with visual impairment⁴.

The majority of children in the UK with severe visual impairment/blindness (determined as corrected acuity worse than 6/60 or 1.1 LogMAR or worse⁵) have additional and often multiple serious motor, sensory or learning impairments and/or serious chronic diseases⁶. The needs of children with ophthalmic disorders vary substantially according to whether these are isolated or part of a complex of other impairments or diseases, as well by the level of visual loss experienced.

Many children with ophthalmic disorders and all with visual impairment (isolated or otherwise) will be under the concurrent care of a range of health, education and social care professionals. Good communication and liaison between the different professionals and agencies involved is the key to delivering comprehensive and co-ordinated care. A multi-disciplinary team approach to achieving this could include the use of ECLOs (Eye Clinic Liaison Officers) and the development of a pathway incorporating a "first point of contact" clinician for children's eye services. A typical



Ophthalmic Services Guidance

ECLO works with staff in the eye clinic and provides a link to the sensory team in social services. They provide support and information to children and families to aid in understanding and coping with the impact of an ophthalmic condition and any associated sight loss¹⁵.

All such multi-disciplinary teams should closely communicate with sensory support services⁷ and provide information about local and national support services and support groups.

Serious visual loss in childhood is uncommon. 6 of every 10,000 children born in the UK each year become severely visual impaired or blind by their 16th birthday and approximately a further 12 become visually impaired (worse than 6/18 or 0.5 to 1.0 Log MAR)⁶. Thus there are at least 4 newly visually impaired children each day in the UK and around 2 per 1000 children in a given population are visually impaired or blind⁸. Children with milder visual loss, unilateral visual problems or eye disease without visual consequences considerably outnumber others within paediatric ophthalmic services and require a disproportionately smaller amount of available resources in the long-term than the minority with visual impairment. The planning of ophthalmic services should explicitly account for the three different 'populations' of children they serve: that with visual impairment as an isolated problem, that with visual impairment as well as other impairments/disorders and that with mild or no visual loss.

Health services for children with ophthalmic disorders should uphold the principles and standards of care established by the UK's National Service Framework for Children¹. A 'needs based' approach, especially in relation to disability, which takes into account personal differences (including those arising from socio-economic and



demographic characteristics) and places the child and the family at the core, should be the paradigm for ophthalmic services for children.

3. Primary Prevention (NSF standard 1: Promoting Health and Well-being, Identifying Needs and Intervening Early)

The College endorses the recommendations of the fourth edition of “Health for all children” issued in 2003⁹ and subsequently in the Child Health Promotion Programme and the Healthy Child Programme (http://www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH_107563) regarding screening, in order to promote early detection¹⁰ of ophthalmic disorders or reduced vision. Parents should be aware that their child is entitled to a free NHS eye examination up to the age of 16 (19 if in full time education) by community optometrists.

3.1 Neonatal examination

The external eyes should be examined and the presence of a red reflex in each eye established by a suitably trained health professional. The parents should be asked if there is a family history of visual disorders – particularly retinoblastoma or congenital cataract. Parents should be asked soon after birth and at each subsequent contact whether they have any anxieties about the baby’s vision. Concerns arising as a result of these procedures should prompt urgent referral to hospital ophthalmic services.

3.2 Screening at age 4 - 5 years:

A visual assessment by an orthoptist should be carried out on all children between the ages of 4 and 5 years. In areas where this is not possible, children should be screened at school entry as part of a programme supervised by an orthoptist⁹. This position is also endorsed by the UK Vision Strategy Screening Action Group.



Screening at 4 to 5 years is primarily concerned with detecting unsuspected visual impairment in one or both eyes. Visual acuity should be tested using a logMAR system to allow statistical analysis and comparison with other studies and programmes.

The gold standard for visual acuity estimation is an age appropriate linear logMAR test. This allows statistical analysis and comparison with age related norms. Children who achieve less than 0.2 LogMAR (6/9.5 Snellen) in either eye, despite good co-operation should be referred⁹.

Feedback on referral outcomes must be sent to the referrer and to the general practitioner. A summary of management should be sent to the general practitioner at the time of discharge.

The service should be subject to regular audit.

3.3 Screening at other ages:

The benefits of screening at other ages - e.g. at 11 – 14 years for myopia, other visual acuity defects and colour vision impairments, are unresolved, and we do not recommend any change to current local arrangements.

3.4 Secondary screening

Secondary screening refers to the assessment of a child with a suspected ophthalmic disorder by a community based professional e.g. orthoptist or optometrist with a view to reducing rates of hospital attendance and providing treatment, where necessary, closer to home.

3.5 High Risk Groups



Targeted clinical surveillance of certain groups at high risk of an ophthalmic disorder is recommended (incorporating a full orthoptic examination, cycloplegic refraction and fundus examination).

These groups include children with:

- Sensorineural hearing impairment
- Neurodevelopmental impairments inc Downs syndrome
- A family history of a childhood onset ophthalmic disorder e.g. retinoblastoma

Where appropriate, these examinations should be performed in community settings.

4. Children and Young People in Hospital (NSF standard 7)

4.1 General

A senior member of staff in each eye unit should be designated the lead for children's ophthalmic services.

Children, young people and their parents should be actively involved in decisions about the child's health and wellbeing, based on appropriate information.

Confidentiality and consent policies should be developed and made explicit to children, young people and their parents.

Every ophthalmic unit should have recognised emergency cover arrangements and access to paediatric advice and facilities.

A senior member of staff should have designated responsibility for screening for retinopathy of prematurity and ensuring arrangements are in place to cover periods of leave.



Ophthalmic Services Guidance

All staff involved with the care of children should be familiar with local and national child protection policies (see Procedures for the Ophthalmologist who suspects child abuse at

<http://www.rcophth.ac.uk/page.asp?section=493§ionTitle=Information+from+the+Paediatric+Sub-Committee+for+Healthcare+Professionals>).

4.2 Paediatric Eye Clinics:

Minimum requirements in relation to working practices and the physical environment include:

- Children should be offered appointments in a timely manner according to clinical need
- The clinic environment should be safe and well suited to the age and stage of development of the child or young person.
- Children and accompanying siblings should have access to facilities for play, toileting and changing, as well as facilities for infant feeding.
- Facilities need to be accessible for all children, with access for wheelchairs and buggies, accessible car parking, clear sign posting and low reception counters.
- Where possible, children should be seen in dedicated children's clinics
- Staff working in the children's eye clinic should have a common core of skills, competencies and knowledge including knowledge of child protection procedures.
- Clinic appointments should be timed so that long waiting times are avoided.

Ophthalmologists should provide ready access to their first available outpatient clinic for those children in whom serious visual disability or ophthalmic disease is suspected by general practitioners or paediatricians.



If significant visual disability is confirmed they should notify the Specialist Visual Impairment Teaching Service and Community Child Health services

There should be ready access to general and specialist paediatricians for assessment and advice.

There should be ready access to investigations and special tests necessary for diagnosis e.g. electrophysiology, neuroimaging, genetic counselling, low vision aids

Whenever children are seen in A & E departments for eye injuries it is important that appropriate provision is made for them (as in outpatients) and information fed back to the district child accident prevention group, if appropriate.

4.3 Hospital Inpatient and Daycase Services

The majority of ophthalmic surgery in children can be performed as a day case procedure.

Children should be cared for on wards appropriate for their age and stage of development.

Close involvement of the family is essential because children in hospital who are separated from their parents are more likely to suffer psychological stress and recover more slowly, than if not separated.

All hospitals, which have children as in patients, should provide somewhere for parents to stay overnight, wash, make drinks, and to sit in privacy.



Written information for parents should be provided covering policies, facilities, particulars of procedures and contact numbers.

4.4 Surgical Services

Surgery should be scheduled in a timely manner according to clinical need

While most ophthalmologists with continuing experience will be competent to perform uncomplicated strabismus and lacrimal procedures in children, other rarer procedures such as anterior segment surgery in children should be carried out by consultants with appropriate specialist training and expertise.

It is recognised that some specialised conditions will be treated by surgeons who are not primarily paediatric ophthalmologists, e.g. subspecialist vitreoretinal surgeons, orbital, lacrimal and oculoplastic surgeons.

Anaesthetic services for paediatric ophthalmic surgery should be provided by anaesthetists with adequate training and continuing experience, as specified by the Royal College of Anaesthetists.

If staff with appropriate training and continuing experience are not available consideration should be given to treating the child in a hospital with the necessary staff.

Units training ophthalmic specialist trainees must ensure that trainees obtain appropriate exposure to paediatric ophthalmology according to the curriculum of the Royal College of Ophthalmologists (<http://curriculum.rcophth.ac.uk/>).



Ophthalmic Services Guidance

In order fully to utilise the skills of experienced surgeons, anaesthetists and nurses, we strongly encourage the concentration of children onto separate lists.

See also: 'Surgery for Children: Delivering a First Class Service'. Royal College of Surgeons of England, 2007 <http://www.rcseng.ac.uk/publications/docs/CSF.html>

5 Services for children who are visually impaired

All eligible children and young persons should be offered certification as sight-impaired or severely sight impaired where indicated¹¹.

Children and young people with a disability should receive timely co-ordinated, high quality child and family centred services, which are based on, assessed needs (including visual impairment) and promote social inclusion.¹²

The majority of children with severe visual impairment and blindness (SVI/BL) have additional non-ophthalmic disorders or impairments. 48% of SVI/BL in the UK is associated with disorders of the cerebral visual pathways.

Visually impaired children and their families need help and support to assist children to develop to their full potential. There is evidence that many families do not have their needs adequately met.⁴

Parents should be informed that developmental guidance for families is available within the Developmental Journal for Babies and Children with Visual Impairment, produced by Early Support. (Early Support is the Government programme which aims to achieve better coordinated, family focussed services for young disabled children and their families.) The Journal will generally be introduced to families by



Ophthalmic Services Guidance

the Specialist Teacher for the Visually Impaired but families can be advised of the Journal's existence and its availability on the internet.¹³

We believe that there is a need in each district for a multidisciplinary team to assess children with significant visual disability such as that described by Hill et al in Liverpool¹⁴. Such a team would include professionals from both health and education. The objectives are, at the earliest possible age:

To assess visual function

- a)** to assess developmental/educational status and decide if it is consistent with the degree of visual disability;
- b)** to evaluate other disabilities in the light of a) and b)
- c)** to offer on-going support and advice to parents;
- d)** to coordinate services, including the appointment of a key worker.

All families should receive an explanation of their child's disability in language that they can understand from an identified specialist doctor, usually the responsible ophthalmologist. Lack of information is a common complaint; more than 60% of parents in the Royal National Institute of the Blind survey said that they had nobody knowledgeable to talk to when they first learned of their child's disability, and 40% claimed never to have had an explanation in terms they could understand.

Counselling should be available to families who want it, to help them explore and come to terms with their feelings about their child's disability. Advice should be available to all parents who need it to enable them to receive disability living allowance and other benefits for visually impaired children.

Parents should be offered help to understand the nature of their child's disabilities and ways in which they can help him or her to develop optimally; the effective use of residual (functional) vision and the development of communication skills and mobility



can be enhanced through challenging play and prevented by unnecessary restriction. This advice needs to be available throughout childhood as children's needs change as they grow older.

Paediatricians and ophthalmologists should seek the views of their patients and families to assess the level of satisfaction with local services and should work with colleagues in other disciplines to remedy deficiencies. They can also encourage the development of parent support groups.

Author: Mike Clarke on behalf of the Paediatric Subcommittee

Reviewed: August 2012 Chris Lloyd, Jane Leitch, and Jugnoo Rahi of the Paediatric Sub-committee

References

- ¹ Department of Health TSO. National service framework for children, young people and maternity services: core standards. National Service Framework. London: Department of Health, Department for Education and Skills, 2004: 30.
- ² Dale N, Sonksen P. Developmental outcome, including setback in young children with severe visual impairment. *Dev Med Child Neurol* 2002;**44**:613-622.
- ³ Read J. Disability, the family and society. Listening to Mothers. Buckingham, UK: Open University Press, 2000.
- ⁴ Rahi J, Manaras I, Tuomainen I, Hundt GL. Meeting the needs of parents around the time of diagnosis of disability in their children: evaluation of a novel scheme for information, support and liaison by key workers. *Pediatrics* 2004;**114**:e477-482.
- ⁵ (WHO) WHO. International Classification of Diseases and Health related Problems. Geneva, 1992.
- ⁶ Rahi J, Cable N. Severe visual impairment and blindness in children in the UK. *Lancet* 2003;**362**(9393):1359-1365.



-
- ⁷ Bent N, Tennant A, Swift T, Posnett J, Scuffham P, Chamberlain M. Team approach versus ad hoc health services for young people with physical disabilities: retrospective cohort study. *Lancet* 2002;**360**:1280-1286.
- ⁸ Rahi J, Dezateux C. Epidemiology of Visual Impairment. In: David T, ed. *Recent Advances in Paediatrics* 19. London: Churchill Livingstone, 2001: 97-114.
- ⁹ Hall D, Elliman D. *Health for all children*. 4th ed: Oxford University Press, 2003
- ¹⁰ Rahi JS, Cumberland PM, Peckham CS; British Childhood Visual Impairment Interest Group. Improving detection of blindness in childhood: the British Childhood Vision Impairment Study. *Pediatrics*. 2010 Oct;126(4):e895-903. Epub 2010 Sep 20.)
- ¹¹ Cumberland PM, Peckham CS, Rahi JS. Blindness certification of children 1 year after diagnosis: findings from the British Childhood Vision Impairment Study. *Br J Ophthalmology*. 2010 Dec;94(12):1694-5. Epub 2010 Sep 2.)
- ¹² *Aiming High for Disabled Children: better support for families*; HM Treasury and DfES, 2007
- ¹³ Early Support: Developmental Journal for Babies and Children with Visual Impairment: www.earlysupport.org.uk
- ¹⁴ Hill A, McKendrick O, Poole J, Pugh R, Rosenbloom L, Turnock R. The Liverpool Visual Assessment team: 10 years' experience. *Child Care Health Dev* 1986;**12**:37-51.
- ¹⁵ http://www.rnib.org.uk/eyehealth/who/eclo/Pages/about_eclos.aspx