

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 and/or visual impairment. The Committee endorses the standards laid out in the recently published National Service Framework for Children, Young People and Maternity Services: Change for Children – Every Child Matters¹.

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

The purposes of ophthalmic health services for children remain:

- Primary prevention – ie preventing the occurrence of visually impairing disease *eg through screening and treatment to prevent cicatricial retinopathy of prematurity*
- Secondary prevention – ie reducing the visual impact of established disease *eg early detection and prompt and effective treatment of infantile cataract or glaucoma, amblyopia, strabismus and refractive error*
- Tertiary prevention – ie maximising functional vision in ‘untreatable’ disease *eg provision of low vision aids for children with congenital eye anomalies or visual stimulation/rehabilitation programmes for children with cerebral visual loss*

Glossary:

Ophthalmologist: a doctor trained in the diagnosis and management, including surgery, of disorders of vision.

Optometrist: a health professional trained to detect and correct refractive errors, to screen for eye disorders and prescribe treatment for some common eye conditions

Orthoptist: a health professional trained in the diagnosis and management of ocular motility disorders, ocular misalignments (squint or strabismus) and amblyopia (lazy eye). Orthoptists are also involved in screening for eye disorders

2. Introduction

To deliver high quality services, it is essential to address the specific needs of children with eye disease and/or visual impairment as well the needs of their families. These needs, which differ from those of adults, are shaped by the following issues unique to childhood or paediatric eye disease:

- A child’s health encompasses their physical, emotional and social development and 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 conditions and their***

management should be viewed in the broader context of general health and development – services should be child-centred.

- Effective partnership between parents and health professionals is central to the successful management of all children with ophthalmic conditions, with, in many situations, the parents implementing the treatment, for example 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.***
- Effective partnership depends on clear communication between parents, children and professionals. ***Health professionals should ensure that information about a child's eye condition 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 professionals 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 (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 conditions 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 children with visual impairment (isolated or otherwise) will be under the concurrent care of diverse health, education and social care/welfare professionals. ***Good liaison between the different professionals and agencies involved is the key to delivering comprehensive and co-ordinated care and a multi-disciplinary team approach to achieving this is, including through use of key worker schemes, is advocated⁷.***
- Serious visual loss in childhood is uncommon, with 6 of every 10,000 children born in the UK each year becoming severely visual impaired or blind by their 16th birthday and probably a further 12 becoming 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 2 per 1000 children in a given population at any time 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 but are, nevertheless, likely to 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 and/or visual impairment 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 now 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 Committee endorses the recommendations of the fourth edition of “Health for all children” issued in 2003 regarding screening for vision defects⁹. 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 districts where this is not possible, children should be screened at school entry as part of a programme supervised by an orthoptist⁹. Screening at 4 to 5 years is primarily concerned with detecting previously undocumented 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, such as the Keeler Acuity Cards or Cambridge Crowded Acuity Cards. 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 referred.

Feedback on referral 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 11 – 14 years:

The benefits of screening at age 11 – 14 years for myopia, other visual acuity defects and colour vision impairments, are unresolved. We recommend that whatever is in place at present continues until this matter is resolved.

3.4 Secondary screening

Secondary screening by a community based Orthoptist involves examining children referred by parents or by other professional staff, whenever a concern is expressed and selecting those who require a more detailed assessment. This results in a substantial reduction in the number of false referrals to ophthalmologists and considerable financial savings.

3.5 High Risk Groups

Clinical surveillance of certain groups at high risk of a treatable visual disorder is recommended. These include children with:

- Sensorineural hearing impairment
- Neurodevelopmental impairments inc Downs syndrome
- A family history of a childhood onset eye disease dominantly inherited ocular disorder e.g. retinoblastoma
- Young people with diabetes

Where appropriate, these examinations can be performed by optometrists and/or orthoptists in the community without the need for hospital referral.

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 eye services.
- Children, young people and their parents should be actively involved in decisions about the child's health and well being, 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 ROP screening and ensuring arrangements are in place to cover periods of leave.
- 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 www.rcophth.ac.uk/members/members-documents/CHILDABU2000).

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 paediatric clinics
- Staff working in the paediatric 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 district visual disability team and community child health services
- 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 subspecialist training and expertise.
- It is recognised that some specialised conditions will be treated by surgeons who are not primarily paediatric ophthalmologists, e.g. retinopathy of prematurity, vitrectomy for trauma.
- 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 registrars and senior house officers must ensure that trainees obtain appropriate exposure to paediatric ophthalmology according to the curriculum of the Royal College of Ophthalmologists.
- In order fully to utilise the skills of experienced surgeons, anaesthetists and nurses, we strongly encourage the concentration of children onto separate lists.

5 Services for children who are partially sighted or blind

- Children and young people with a disability should receive co-ordinated, high quality child and family centred services which are based on assessed needs (including visual impairment) and promote social inclusion.
- 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.
- 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 Liverpool¹⁰. The objectives are, at the earliest possible age:
 - a) to assess visual function
 - b) to assess developmental/educational status and decide if it is consistent with the degree of visual disability;
 - c) to evaluate other disabilities in the light of a) and b)
 - d) to offer ongoing support and advice to parents;
 - e) 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.

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Acknowledgements

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