# Ensuring Support: Certification and Registration in children and young people with Vision Impairment in England

## Introduction

The Certificate of Vision Impairment (CVI) formally certifies a person as either sight impaired/partially sighted (SI) or severely sight impaired/blind (SSI). The eligibility criteria are the same for children as for adults. The purpose of the CVI is to provide a reliable route for someone with vision impairment to formally be brought to the attention of social care. In addition epidemiological analysis of CVI data provides information on the prevalence of vision impairment. Registration as blind or partially sighted is a voluntary choice. The registers are usually held by local authority Social Service Departments (SSD). The purpose of these registers is to help local authorities plan and provide services for people who are vision impaired.

The study reported here investigates the certification and registration (C&R) process for children and young people aged from 0–17. It follows on from a similar study with adults, which found a number of barriers and delays to C&R and as a result made specific recommendations for different stakeholder groups in order to improve the process (Boyce, 2012).

While we expected to find similarities between the child and adult process, we also anticipated some differences as the role of professionals may be different. For example, while some ophthalmologists who work with children also specialise in paediatrics, others may work mainly with adults. Pathways to support may differ too, as in addition to health and social care professionals, qualified teachers of children with vision impairment (QTVI) from the local authority education vision impairment (VI) advisory service provide support to blind and partially sighted children and their families.

## 2. Method

Telephone interviews were carried out with professionals involved in the C&R process, and with parents of children who were registered as SSI or SI. The health professionals came from hospitals in five areas in England and included: consultant ophthalmologists (some with and some without a specialist interest in paediatrics), orthoptists, optometrists, Eye Clinic Liaison Officers (ECLOs) and administrators. Eight local authorities (LAs) that were linked geographically to one or more of the five sites also took part. The local authority professionals interviewed were QTVIs working in VI services, and social services professionals working with children registered as SI or SSI. We also interviewed 26 parents from across the whole of England and not just the participating hospital and LA areas.

## Key findings from the research

### 3.1 Finding 1: Not all CYP who are eligible are being certified and registered

There is evidence that not all eligible children are being certified, and of those that are certified not all are subsequently registered. This means that children and families may be missing out on important financial and practical support.

### 3.2 Finding 2: The C&R process for CYP is highly inconsistent across England

There was wide variation across the hospitals and local authorities studied in the procedures for certification and registration and in the role played by various professionals. Interviews with parents – who came from across the whole of England – also found a wide variation in procedures and policies as well as the timing and nature of support for children and families.

### 3.3 Finding 3: There is inconsistent practice for babies and children with vision impairment and additional complex needs

It appears that children with complex needs are not always referred to ophthalmology departments for assessment by an appropriate professional. Those who have been identified as having vision impairment can often wait months or even years for the offer of certification.

### 3.4 Finding 4: Referral for specialist support was often delayed

Babies and young children with vision impairment require the intervention of a specialist – usually a QTVI – as early as possible to support their cognitive development, communication, social and independence skills. Referral to the local authority VI service should take place as soon as a baby or child is identified as having a problem with their vision. This should not be dependent upon certification. While some ophthalmologists and other health professionals understood the need to refer babies and young children for specialist support as soon as possible, according to both ophthalmologists themselves and to parents, referrals were often delayed and/or dependent upon certification. Ophthalmologists who had not had specialist training in paediatric ophthalmology were often unaware of referral pathways and of the needs of children and their families, which often caused unnecessary delays in the provision of support.

### 3.5 Finding 5: ECLOs and other intermediary roles are under-used

Intermediaries such as specialist nurses, Eye Clinic Liaison Officers (ECLOs) and Family Support Unit workersprovided practical and emotional support and information for parents in the early stages of identification of their child’s vision impairment, which parents very much valued. As they have a key role in ensuring that CYP are referred to local authority education and other services for specialist support their early involvement is important. They can also save clinicians time by answering parents’ non-clinical questions, as well as dealing with administrative tasks in the certification process. However, hospitals did not always take full advantage of these intermediary roles and referring parents to them was not consistent as it was often a subjective decision made by individual ophthalmologists.

### 3.6 Finding 6: Variable support from social care services

The purpose of the CVI is to provide a reliable route to support but the support offered to children and their families by social services (SS) is inconsistent with some areas offering assessments and follow-up support and others not offering any support or offering little beyond a contact letter and the registration card. In many SS departments there is a substantial lack of contact with and understanding of children with VI. Only one out of the eight LA areas studied had a fully co-ordinated approach between health, social care and education.

Those few parents who had received support from social services appreciated it enormously. Support included input from a social worker (who was highly valued), respite care, and help with re-housing.

### 3.7 Finding 7: The most valued professional was the QTVI

QTVIs were the primary source of information and support for CYP and their families. QTVIs provided support and information on education, parenting skills, funding/welfare, social opportunities and emotional support. Parents consistently stated the support provided by QTVIs was the most valuable support and help they received.

However there were examples from some parents of poor practice; some CYP only received support from QTVIs after their parents repeatedly requested it.

### 3.8 Finding 8: Value of certification and registration to parents

Parents of children who are registered all said that registration was important to them. Benefits included financial benefits (such as DLA), having clear evidence that their child was SSI/SI when this wasn't necessarily apparent (e.g. in the case of a child with complex needs), and in a few cases it was their passport to support.

### 3.9 Finding 9: Not all CYP who are eligible are being registered

The registration system for CYP appears to be in a poor state. Four of the seven local authority SS departments held multiple versions of the CYP registers; some LAs did not even know where the registers were located. Inaccurate registers will prevent local authorities from planning effectively for children with VI who have the highest levels of need. Without knowing how many CYP have severe VI it may be difficult to determine budgets for specialist services such as QTVIs.

## Conclusions

The findings from this study demonstrate that the C&R processes for children and young people are highly inconsistent across England. While parents of children who were registered spoke of the benefits this had brought them, not all eligible children were certified by ophthalmologists, and not all local authorities maintained a register of children. The consequences are that children and their families may be missing out on important financial and practical support; and local authorities that are failing to maintain registers may lack key data for strategic planning of local services.

Early intervention and support is essential for babies and young children with vision impairment to support the development of their social, cognitive, communicative and independent mobility skills. The key professional in providing such support is the local authority specialist teacher for children with vision impairment (QTVI). While referral to both education and social care services should not be dependent upon certification, many parents in this research did experience delays in support until after their child had been certified and registered.

Hospitals under-utilise intermediary staff such as an ECLOs, specialist nurses and family support unit workers, who have a key role to play in providing emotional and practical support to families, ensuring prompt referral to education and other services for specialist support, and assisting with the administration of the CVI.

There were examples of good practice, where CYP and their families received good quality support early and in a timely manner and where health, social care and education services had established multi-agency working, although only one area had a recognised pathway to support for those who were not issued with a CVI. It is important to build upon these examples of effective practice to ensure that all local authorities and hospitals have an established pathway to support for children and young people with vision impairment and their families, as well as clear certification and registration processes that are understood by staff at all stages of the process.

## 5. Further information

The executive summary can be downloaded from:

For further information contact [sue.keil@rnib.org.uk](mailto:sue.keil@rnib.org.uk)

© RNIB 2015

### About RNIB’s research

RNIB is a leading source of information on sight loss and the issues affecting blind and partially sighted people. Our Research and Knowledge Hub contains key information and statistics about blind and partially sighted people including our Sight Loss Data Tool, which provides information about sight loss at a local level throughout the UK. You’ll also find research reports on a range of topics including employment, education, technology, accessibility and more. Visit our Knowledge and Research Hub at: **rnib.org.uk/research**