# Ensuring Support: Certification and Registration in Children and Young People in England

## Executive Summary

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## Executive Summary

### Introduction

This research examines the current certification and registration processes for children and young people (CYP) and explores these pathways to support. This research replicates a similar study examining the certification and registration processes (C&R) in adults and investigates the same processes in CYP aged from 0 – 17.

### Method

Findings are based on 78 telephone interviews involving parents of CYP with vision impairment (VI) and professionals involved in C&R. 26 parents were interviewed and 52 professionals (29 from Healthcare, 8 from Education and 15 from Social Services).

Certification processes within hospitals in five areas of England, including both District General Hospitals and Tertiary Referral Centres, and pathways to support in eight local authorities associated with the hospitals were studied.

### Principal Findings

#### 3.1 Not all CYP who are eligible are being certified

Not all CYP who are eligible are being certified. This means that children and families may be missing out on important financial and practical support. CYP with severe VI should be certified (and subsequently offered registration) when they are eligible and support should be offered when it is needed.

#### 3.2 Current support and information provision is inconsistent – excellent in some areas but poor in many

Effective C&R processes should lead to an offer of support and information to CYP and their families as soon as a severe VI is identified. Many parents referred to either the complete lack, or poor quality, of information provided by ophthalmologists and other healthcare professionals during the Certification process followed by a lack of information and support from local authorities.

#### 3.3 The certification process for CYP is highly inconsistent across England

Certification is not always offered consistently, despite national guidelines. There is wide variation across the hospitals studied in the procedures for certification. Interviews with parents – who came from across the whole of England and not just the participating sites – also indicated a wide variation in procedures.

There is a difference in practice between paediatric ophthalmologists and ophthalmologists who work mainly with adults in their approach to certification of children and their understanding of the benefits of registration for children and their families. Compared to paediatric ophthalmologists, the other ophthalmologists in this study, who see CYP less often, certified fewer children in a year, were more reluctant to discuss certification with parents and were more likely to hesitate and delay the offer of certification.

In 2002 the Department of Health recommended that the Certificate of Vision Impairment (CVI) (at that time the BD8) should be sent to the social services department “normally within five working days”. The Royal College of Ophthalmologists does not recommend timescales to complete certification but instead states ‘an important component of good clinical care by ophthalmologists is the offer of a Certificate of Vision Impairment to eligible patients. The College encourages its members to promote the uptake of the CVI amongst patients who are likely to benefit from it and to facilitate the process of registration as far as it is in their power to do so’.

#### 3.4 There is inconsistent practice for children with vision impairment and additional complex needs

There is inconsistent practice in relation to children with vision impairment and additional complex needs. They may not be referred to ophthalmology or offered an eye examination by an appropriate professional. Those who have been identified as having problems with their vision can often wait months or years for the offer of certification – despite being eligible.

#### 3.5 ECLOs and other intermediary roles that are valued by parents are under-used

The support provided in the early stages and during the certification process by ECLOs and other intermediary roles such as specialist nurses and family support workers is highly valued by parents but inconsistently offered because referral to these practitioners was often a subjective decision made by individual ophthalmologists. As ECLOs have a key role in ensuring that CYP are referred to local authority practitioners such as the qualified teacher of children with vision impairment (QTVI) to support early development and provide specialist education provision their early involvement is important.

ECLOs are cost effective, saving clinicians time by answering parents’ non-clinical questions, as well as dealing with administrative tasks in the certification process.

#### 3.6 Parents received support from social services and visual impairment teams only upon formal diagnosis and the offer of the CVI

Babies and young children with vision impairment require the intervention of a specialist practitioner as early as possible to support their cognitive development, communication, social and independence skills. Effective C&R processes result in the provision of early support and information soon after a CYP is identified as having a severe VI and health professionals in the areas studied stated they referred children to specialist services before issuing a CVI. However the majority of parents, whose children were treated in ophthalmology departments across England, reported they only received support from both social services and visual impairment teams upon formal diagnosis, which can take time, and the offer of the CVI. The process of securing a diagnosis should be separate from the process of offering support – too often the two were the same and this led to delays in early intervention.

The Qualified Teacher of Children with Vision Impairment (QTVI) has a key role in supporting CYP. The type of information parents are desperate for is specific and practical information on how best to parent a child with VI - only QTVIs provided this support and their expertise was highly valued by parents. Parents consistently stated the support provided by QTVIs was the most valuable support and help they received.QTVIs provided support and information on education, parenting skills, funding/welfare, social opportunities and emotional support. **Entitlement to support from a QTVI is independent of certification and registration, and referral to the VI service may precede or run in parallel with the C&R process.**

The compassion shown by ophthalmologists, orthoptists, optometrists and ECLOs was clearly apparent but this is not enough – these sentiments need to translate into actions so that health professionals refer CYP with severe VI promptly and consistently to the support they need to secure the best start to their lives. **Only one area had a recognised pathway to support for those who were not issued with a CVI**. The DH has a recommended pathway for referral prior to certification, using the Referral of Visual Impairment (RVI). Although designed primarily for use with adults it can be used with children as well. This is obviously not well used and there was no evidence of use of the Vision 2020 UK Pathway for children and young people with vision impairment and their families either, or of local agreements with VI services.

#### 3.7 The support offered by social services for CYP after Registration is highly inconsistent

Once received by the local authority social services (SS) department, the CVI should act as a referral for a social care assessment within four weeks. Children and young people with vision impairment are defined as disabled, and therefore come into the category of ‘children in need’. Local authorities have a duty to safeguard and promote the welfare of children in need and there is a range of services that they can provide. However, the support offered by SS after Registration is widely inconsistent – almost entirely absent in some areas but excellent in others. In many SS departments there is a substantial lack of contact with and understanding of children with VI.

Parents in some areas were offered assessments and follow up support while others offered no support or little beyond a contact letter and the registration card. Close to half of the parents interviewed were not contacted at any point by Social Services (SS). Only one out of the eight LA areas studied had a fully co-ordinated approach between health, social care and education.

Yet the few parents who were given support by SS valued this highly. Support included input from a social worker (who was highly valued), respite care, and help with re-housing.

On the whole, the specialist support offered by QTVIs was more consistent than that of SS however there were examples of poor practice. Despite the fact that entitlement to specialist educational assessment and support comes under Special Educational Needs and Disability (SEND) legislation and is separate from C&R, some CYP who are certified and registered only received support from QTVIs after their parents repeatedly requested it.

#### 3.8 Not all CYP who are eligible are being registered

Many local authorities are not updating or maintaining the CYP registers. Four of the seven local authority SS departments studied held multiple versions of the VI register for CYP and some areas 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 education and social care services.

The failure to register CYP also denies children and families the benefits that come with registration. Not only were parents empowered by having their child registered, but they appreciated the practical and financial benefits that registration provided. 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.

### 4. Conclusion

There were examples of good practice, where CYP and their families received good quality support early and in a timely manner. However, though the sample was self-selecting, there were far more examples of parents waiting months, sometimes years for support – even after their child was certified.

The 78 interviews with parents, health / education and social care professionals demonstrated that **the C&R processes for CYP is highly inconsistent across England**. The compassion shown by ophthalmologists, orthoptists, optometrists and ECLOs was clearly apparent but this is not enough – these sentiments need to translate into actions so that CYP with VI are **promptly and consistently referred to the support they need to secure the best start to their lives**.

### Recommendations

#### 5.1 Ensure all eligible CYP are offered certification and registration

* Involve ECLOs in certification to co-ordinate the process and ensure speedy referral to social services
* Where there is no ECLO, involve orthoptists and nurses to co-ordinate the certification process
* All professionals involved with CYP with VI and their families at every stage of the pathway should understand the benefits of C&R and be able to explain these to parents
* Establish direct referral routes to social services based on DH recommended timescale of five working days
* Social Services to contact the family within two weeks of receiving the CVI (then BD8), as per DH guidelines, and to offer assessment within four weeks from the date of referral.

#### 5.2 Health professionals should refer all babies and children to local authority vision impairment (VI) specialist education teams as soon as severe vision impairment is identified

* Early intervention for CYP with vision impairment is crucial. Vision must be stimulated to reach its full, useful potential: it is important for a child to make use of any remaining vision. Referral to professionals who can help parents to support children with vision impairment must not be delayed.
* Designate a member of staff within the Eye Clinic (such as an ECLO, specialist nurse or family support worker) to be the first point of contact for providing emotional and practical support for CYP and families.
* Establish direct referral routes to local authority VI teams based on DH recommendations (such as the Referral of Visual Impairment, RVI), or locally developed agreements, upon identification of VI, not when diagnosis occurs.

#### Implement the National Screening Guidelines for VI for all children

#### 5.4 Encourage joint working to better address needs of CYP with VI

A recommended pathway is:

Ophthalmologist confirms first indication of severe vision impairment

ECLO refers to Local authority VI team for support and social care where appropriate

Ophthalmologist refers to ECLO or equivalent

Confirmation of diagnosis by ophthalmologist / orthoptist

Where eligible, ophthalmologist initiates certification and refers to ECLO

ECLO processes certification and refers to social services for registration and support

#### 5.5 Offer information consistently to CYP with severe VI and their parents

* Improve information available to parents in and outside of hospitals.
* Make it available online as well as hard copies. Ensure it is available in accessible format and easily located.
* Children’s VI charities to work together to provide comprehensive website/information to parents of CYP with VI.

#### 5.6 Monitor the role CVIs play in the new Education, Health and Care Plans

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