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

March 2015

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Report commissioned by the Royal National Institute of Blind People

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## Glossary of Acronyms

CYP – Children and Young People

C&R – Certification and Registration

DGH – District General Hospital

DLA – Disability Living Allowance

SSI - Severely Sight Impaired (Blind)

SI - Sight Impaired (Partially Sighted)

VI – Vision Impairment

### Interviewees are described using a number and the following labels:

Par – Parent

Oph – Ophthalmologist

QTVI – Qualified Teacher of children with Vision Impairment

Opt – Optometrist

Orth - Orthoptist

ECLO – Eye clinic liaison officer and related roles (e.g. Family

Support Unit)

Adm – Secretaries, Administrators

Nur – Nurses

SS – Employee in social services (includes managers,

rehabilitation officers, administrators)

## Executive Summary

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

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

Not all CYP who are eligible are being certified. CYP with severe VI should be certified (and subsequently offered registration) when they are eligible and support should be offered when it is needed.

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

Effective C&R processes should offer support and information to CYP and their families as soon as a severe VI is identified.

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’.

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.

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

Certification is not always offered consistently, despite national guidelines. 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.

#### 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.

#### 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.

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

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. 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.

#### 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 after Registration is widely inconsistent - close to half of the parents interviewed were not contacted at any point by Social Services (SS), although the few who were given support by SS valued this highly. The support offered by SS is 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.

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.

#### 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. Recommendations

### 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.

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

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

A recommended pathway is:

Ophthalmologist confirms first indication of severe vision impairment

Ophthalmologist refers to ECLO or equivalent

Confirmation of diagnosis by ophthalimologist / orthoptist

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

Where eligible, ophthalmologist initiates certification and refers to ECLO

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

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

## 1 Introduction

The Certificate of Vision Impairment (CVI) formally certifies a person as either sight impaired (partially sighted) or severely sight impaired (blind) – the eligibility criteria are the same for children as for adults (see Appendix A). Certification and registration are two separate processes and involve a number of stages. Firstly, the CVI is completed by a consultant ophthalmologist who establishes a patient’s eligibility for certification as either SI or SSI, based on visual acuity and visual fields. The consultant ophthalmologist is ultimately responsible for issuing the CVI however others help to complete it including; registrars, nurses, CVI teams, ECLOs, optometrists and secretaries.

The completed CVI is forwarded to the local Social Services Department who ‘offer’ registration, as it is a voluntary choice. If a child or young person (CYP) is not already known to social services as someone with needs arising from their vision impairment, the CVI should act as a referral for a social care assessment, leading to the offer of rehabilitation support. Social Service Departments are mandated to maintain a register of blind and partially sighted people, so once the CVI is received, the local authority should add each CYP to the SSI or SI register. The purpose of the CVI is to provide a reliable route for someone with sight loss to formally be brought to the attention of social care.

However, certifying and registering someone as Severely Sight Impaired (SSI) or Sight Impaired (SI) is not straight-forward: the complexity of these processes can contribute to the decline in the number of eligible people being both certified and registered.(1) This report presents findings from research that replicates a similar study examining the certification and registration processes (C&R) in adults and investigates the same processes in children and young people aged from 0 – 17 (reflecting the ages published in the official registration figures). It explores the barriers to certification and registration of children and young people in England.

Two thirds of childhood vision impairment was present from birth or diagnosed in the first year of life.(2) Babies and young children with vision impairment require the intervention of a specialist as early as possible to support their cognitive development, communication, social and independence skills. Vision develops when it is used and must be stimulated to reach its full, useful potential.(3) Therefore, it is important for a child to make use any remaining vision, and for parents to be provided with support and information to enable this to happen. It is important that CYP are referred as soon as possible to support development and give every child and young person the best start in life. This research will explore the role of C&R and whether or not it helps or hinders this referral process.

The data provided by the C&R processes is useful for two reasons:

* Helping epidemiologists to understand the causes and prevalence of childhood VI- the Public Health Indicator for preventable sight loss is based on the number of certifications per 100,000 population.
* Providing accurate data of CYP with the severest levels of VI at local authority level – enabling them to accurately plan local services.

### 1.1 Counting VI in CYP

In England many changes are occurring that affect CYP with vision impairment – notably the Children and Families Act 2014. That strategic policies and all service planning should be based on reliable data is accepted. The certification and registration figures provide important information about the number of CYP with the severest levels of VI and the highest levels of need, as well as providing epidemiological information about causes and prevalence of VI in CYP. CYP with VI require a range of specialist education and other support (e.g. mobility and independence/ habilitation training).

Those commissioning services should monitor certification and registration figures for CYP, indeed it is unclear how local authorities will be able to plan effectively without knowing the number of children with severe VI in their area.

#### Table 1 Number of overall and new registrations of CYP 2003-14 (4)

|  |  |  |  |  |  |  |
| --- | --- | --- | --- | --- | --- | --- |
|  | All registrations (SSI or SI) age 0-4 | All registrations (SSI or SI) age 5-17 | **All registrations (SSI or SI) age 0-17** | New registrations (SSI or SI) age 0-4 | New registrations (SSI or SI) age 5-17 | **New registrations (SSI or SI) age 0-17** |
| 2003 | 1,310 | 7,460 | **8,770** | 350 | 585 | **935** |
| 2006 | 1,090 | 7,535 | **8,625** | 335 | 480 | **815** |
| 2008 | 1,505 | 9,115 | **10,620** | 380 | 600 | **980** |
| 2011 | 1,245 | 8,390 | **9,635** | 375 | 515 | **890** |
| 2014 | 1,365 | 8,170 | **9,535** | 420 | 540 | **960** |

As can be seen from Table 1, between 2003 and 2014 there has been considerable fluctuation in the overall numbers of CYP registrations. The number of new registrations for 0-4 year olds has however, been quite stable (with a steady increase in new registrations over this period) although this is less the case for CYP aged 5-17.

An analysis of the data on children registered as blind or partially sighted between 1982 and 2011 found that the annual incidence of new registrations has doubled over this period to 0.041% children and young people registered as blind/SSI and 0.059% partially sighted/SI.(5) This gives a total 0.1% annual incidence of new paediatric registrations (i.e. the proportion of children and young people diagnosed as blind or partially sighted within the period of one year).

Commissioners should also note that even though the overall number of registrations is increasing there is evidence this is still an underestimate due to under-registration of children and there is ample evidence this is occurring. Comparing certification and registration figures for children within the same year, we know that in England in the year 2010/2011 a total of 1,154 child CVIs were issued.(6) In the same year, 890 children and young people aged 0-17 were registered as blind or partially sighted.(7) Based on these figures, just under a quarter of children who were certified were not subsequently registered that year. There is also evidence that certification figures under-estimate prevalence. The British Childhood Vision Impairment Study found close to 40% of children identified with severe VI / blindness were not certified a year after diagnosis.

### 1.2 CYP with additional needs

A significant proportion of children with a VI have additional complex needs and/or learning disabilities. Calculating the number of CYP with complex needs or additional disabilities is difficult as they are more likely to be missed in prevalence studies. The most recent registration statistics in England record only one in four CYP registered as SSI or SI as having additional disabilities although recent research concludes at least 50% of children with vision impairment have other disabilities and/or health problems which may cause difficulties when assessing acuity and visual field.

It is important to better understand the prevalence of VI in children with complex needs because the number of CYP with additional needs is expected to increase as the number of treatable or preventable disorders (e.g. retinopathy of prematurity and congenital cataract) declines and the number of untreatable disorders (e.g. cerebral sight problems) increases – linked to the increasing survival of premature and very low birth weight babies and children with major anomalies (e.g. complex neurological and metabolic diseases and malignant disease).(8) As such, if the number of these children with VI is likely to increase, it is useful to make efforts now to more accurately reflect VI in all CYP via C&R processes and related prevalence and incidence statistics.

### 1.3 Growing up with vision impairment

The prevalence of VI in CYP is low compared to that of adults - who account for the vast majority of people living with VI. However the impact of living with VI for a lifetime raises its own issues, and support and information should be offered as soon as needed.

The principal reason for the delay in CYP receiving such support is the process of diagnosis and the delays in referring from health to other agencies. Most children with vision impairment have conditions that are present from birth or diagnosed in the first year of life. As such, they should be identified as requiring support before they reach school yet the prevalence of children with VI (based on those on local authority VI service caseloads) peaks at primary school age – suggesting that problems become evident when children reach reading age or that teachers rather than ophthalmologists are identifying children with a VI who have support needs in school. It seems that clinicians in hospitals are not referring these CYP to support, via certification or any other route.

Evidence shows early diagnosis of childhood vision impairment is a key factor in CYP receiving early intervention and minimising the functional impact of VI. Support is particularly important in the first two years of life for CYP with severe VI as the development of social and communication skills can be seriously impeded. Without specialist support CYP with VI are at serious risk of poor developmental outcomes across a range of emotional and social wellbeing indicators.

### 1.4 Aims of the report

The aim of this research is to examine the current C&R processes for CYP and to compare their pathways to support. In particular, this research will investigate:

* Parents' experiences of the process from certification to registration of children and young people
* What benefits parents obtain from having their children registered as blind or partially sighted
* The role of ophthalmologists (both paediatric ophthalmologists and those who work primarily with adults) in the process of certifying children as blind or partially sighted, and their understanding of:
  + the process of certifying children
  + the benefits of certification and registration for children and their families
  + their approach to certification (e.g. at what point this should occur)
  + whether the presence of other disabilities is a factor in clinicians' decision not to offer certification
* The role of social care professionals in the process, their views of the benefits of registering children and what barriers there are to this occurring
* How referral to local authority VI teams and specialist teachers (QTVIs) is linked to the C&R process.

Whilst this report focuses on the situation in England, its findings are relevant to the wider UK context.

## 2 Method

This project aims to identify the key factors in the C&R processes for CYP. It is a qualitative study involving interviews with parents and key professionals and does not seek to be a representative analysis of the C&R processes across England.

RNIB commissioned the research and brought together an advisory group that included health, education and social care professionals. The advisory group aided in developing the four interview topic guides (health care professionals, education professionals, social care professionals and parents).

This research was deemed a service evaluation therefore it did not require NHS ethics approval from each hospital.

### 2.1 Areas studied

Hospitals in five areas in England were selected for inclusion based on two factors; the most recent registration rates and whether or not they employed specialist paediatric ophthalmologists. The sample deliberately includes District General Hospitals and Tertiary Referral Centres. Eight local authorities that were linked geographically to one or more of the five sites also took part. Specialist education services in seven local authorities associated with the hospitals and representatives from seven SS departments were interviewed. In one area representatives from different social services and education departments were interviewed resulting in professionals from eight local authority areas being interviewed. The sample is a purposive sample aimed at providing an overview of the C&R processes in each of the five NHS areas.

Three of the five hospital areas employ at least one ophthalmologist with a specialist interest in paediatrics. In two of these areas general ophthalmologists see children – they do not have a special interest or training.

Of the eight local authorities studied, one area did not have any CYP registered at all (in the year ending 31 March 2014). Three of the eight local authorities studied did not have any new registrations in CYP (under the age of 17) – two of the areas with no new registrations were large urban areas and a comparable urban area studied had over 30 new registrations in the same period.

### 2.2 Interviews

Two cohorts were studied. Firstly, professionals involved in the C&R processes were interviewed. This cohort included:

* Health professionals working with the C&R processes (ophthalmologists, orthoptists, optometrists, rehabilitation officers, Eye Clinic Liaison Officers (ECLOs) and administrators)
* Specialist teachers (QTVIs) working in local authority education VI services
* Social services professionals working with children registered as SI or SSI.

As stated above, interviewees from eight local authorities are discussed as professionals from eight local authority areas being interviewed.

Secondly, parents of children and young people registered as SI or SSI were interviewed. Parents were recruited via invitation calls sent from RNIB and Action for Blind People (posted on their websites) and letters sent by interviewed QTVI teachers. The request for interviews was also placed on social media websites of parent support groups – this was beyond our control but was very welcome as it led to a number of parents being interviewed. Parents were therefore recruited from across the whole of England and not just the participating hospital and LA areas.

The original aim of the project was to interview parents of CYP certified within the last two years however this had to be extended as recruitment proved difficult. Of the 26 parents interviewed:

* 10 parents with children certified over 5 years ago
* 12 parents with children certified between 2-4 years ago
* 3 parents with children certified under 2 years ago
* 1 parent with child certified within the last year.

All interviews were held between March and July 2014 and completed over the telephone by the researcher. Interviews lasted between 10-50 minutes. Interviews were recorded (in agreement with the interviewee) and transcribed. Analysis of interviews uses both an inductive and deductive coding framework. No qualitative software is used.

The advisory group helped design the interview questions. See Appendix 2 for a list of interview questions.(9)

### 2.3 Sample size

A total of 78 interviews were held with (Table 2):

* 29 health care professionals
* 8 ophthalmologists held specialist training in paediatrics
* 15 social care professionals
* 8 education professionals
* 26 Parents with 28 children with VI (2 parents with 2 children with VI).

Interviewees are described using a number and the following labels:

* Par – Parent
* Oph – Ophthalmologist
* QTVI – Qualified Teacher of children with Vision Impairment
* Opt – Optometrist
* Orth - Orthoptist
* ECLO – Eye clinic liaison officer and related roles (e.g. Family Support Unit)
* Adm – Secretaries, Administrators
* Nur – Nurses
* SS – Employee in social services (includes managers, rehabilitation officers, administrators)

#### Table 2 Number of interviews

|  |  |  |  |
| --- | --- | --- | --- |
| Hospital Staff | Education | Social Services | Parents |
| 12 Consultant Ophthalmologists | 7 QTVI | 6 Managers | -26 parents with 28 children |
| 3 ECLOs | 1 Manager | 5 Rehabilitation Workers | -7 CYP with complex needs |
| 1 Optometrist |  | 3 Administrators | -18 diagnosed under age 1, 10 certified under age 1 |
| 5 Administrators |  | 1 social worker | -Ethnicity: 26 white, 2 Asian |
| 6 Orthoptists |  |  | -12 girls, 16 boys |
| 2 Nurses |  |  |  |
| **Total: 29** | **Total: 8** | **Total: 15** | **Total 26** |

The terms ‘certification’ and ‘registration’ were used incorrectly and inconsistently by most interviewees and have been amended in the text to provide clarity.

### 2.4 Research limitations

The original aim of the research was to interview parents from the same areas as the professionals (similar to the sample researched for the adult C&R project).(1) As there are fewer CYP certified compared to adults, it was decided to widen the sample to include parents of CYP certified in all parts of England. As such, it is difficult to provide a snapshot of each area as evidence is only available from what professionals (health, education and social care) said and we are unable to verify their statements with related parents’ opinions and experiences of this service. Despite this limitation, the research is able to identify key themes arising from each interview cohort.

Another limitation is the parent interviews were originally to be held with parents of CYP certified and registered within the last two years. As recruitment was difficult, we widened the interview sample to include all parents of CYP who are certified and registered. The detailed memories of some parents was, at times, imprecise as the certification process took place a number of years ago (10) but on the whole, parents vividly recalled the day their child was certified and the subsequent services they did/not receive.

## 3 Findings

This findings section first examines the process of certification and barriers in both the process of offering the CVI and completing it. During the time of diagnosis parents report they are eager for support and information yet too often they are either not provided with information and support or that referrals take months or even years. Some of these delays in access to support are specific to CYP and others are similar to those facing adults.

Secondly, it assesses the process of registration, showing it is not a consistent route to support. Throughout the C&R processes, in many areas that took part in the study there was a lack of clarity around the role and responsibilities of social services , despite the fact that this is set out clearly in ADASS guidelines.(11) However when SS are involved, parents find their support invaluable. In addition to the offer of support from SS being inconsistent, there was inconsistency across the LAs studied in their approach to maintaining the registers for CYP, with several not regarding this as a priority despite their importance for effective planning of services for children with high levels of need.

The purpose of the CVI is to provide a reliable route to support - **the CVI does not appear to provide this reliable route for CYP**.

Parents were often desperate for support and information, and they wanted skilled and well-timed support. In this study parents repeatedly stated the value and significance of QTVIs in Local Authority Vision Impairment (VI) teams, who provided high quality support quickly after the identification of severe VI in their child. In fact **QTVIs**, not rehabilitation officers or social workers in Social Service departments, were **the main providers of practical support to parents.**

### 3.1 The Certification Process

#### 3.1.1 What influences ophthalmologists’ offer of certification

##### Guidelines

In the majority of cases, ophthalmologists were the professionals to first mention the possibility of CYP being eligible for certification: 18 out of 26 parents reported that ophthalmologists were the first to offer the CVI. When asked what influenced their offer of the CVI, **all ophthalmologists referred to the criteria issued by the Department of Health** (Appendix B).

‘If they don’t fit in the criteria, than I don’t offer.’ (Oph1)

‘They do have to meet certain requirement because there are standards you have to do when you write the form, it asks their vision, their field, whether their vision changes in lighting conditions. You can’t just say it’s 6/6 and they want help at school unless they’ve got very constricted fields. So you are constrained by the requirements of the form.’ (Oph6)

**Ophthalmologists who certify numerous children in a year had more flexible attitudes to certification** and also considered more functional criteria.

‘I tend to be rather flexible with interpreting the guidelines. I don’t think visual acuity is the best way of doing it in children. For instance, children with nystagmus might have better vision than 6/18 but they obviously have visual problems in terms of tracking and visual perception. Same with some of the milder forms of cerebral VI where their visual acuity can be good but they are confronted with a real world where they are overloaded with visual information and they really struggle. I tend to adopt a more functional approach to it. Based on fact that acuity are guidelines rather than strict legal definitions.’ (Oph7)

‘With all cases you take into account not only the visual acuity in the clinic, you take in account the visual fields, whether night blind, whether they’ve got nystagmus, which will worsen when they are anxious, whether they are sensitive to light so vision is worse outdoors...You’ve got to be close to it, but we’ve got a fair bit of flexibility.’ (Oph5)

##### Parents ask for and want certification

Close to a third of parents (8) interviewed stated they asked for their child to be certified because they wanted to access support. Most of these parents learned about the benefits of certification from other parents.([[1]](#footnote-1)) One parent, whose child lost their vision due to a detached retina, waited a year for the final diagnosis. This mother very much wanted support sooner – and as it came after C&R, she wanted her child certified much earlier:

‘I think we should’ve been offered something sooner, but it’s easy to say that in retrospect but actually he was by then two and half years and we had no idea and not a clue then what to do with this child who was now blind.’ (Par17)

A parent of two children with VI said:

‘I think because we had, not a battle, to get my eldest son certified, we did have to go back to them a couple of times and a couple of times they’d said we didn’t think it was appropriate or they didn’t think it was the right time, not that he didn’t meet the criteria, but they just didn’t think it was beneficial. Because we didn’t know as much then as we do now, we didn’t question that…It was on the third asking that the doctors agreed, for eldest…I think maybe they thought we were just trying to get money out of the government.’ (Par24)

Two of the three parents who had a child move from being certified as SI to SSI asked for the change in certification.

‘His ophthalmologist always did say from the beginning that she thinks that it’s not going to change, it is what it is. But there have been slight fluctuations. On our last appointment I was speaking to her because I wanted to get a blue badge and I was looking through all the LA information and it was very hard to get it if your child wasn’t SSI or couldn’t walk at all… She looked back through his notes and said ‘Well I can certify him as SSI’ and I said ‘ok, then do that’.’ (Par14)

It is notable that **very few parents decline the offer of certification**. Ophthalmologists consistently remembered only one or two significant examples in their careers – emphasising the infrequency of parents declining the offer.

‘Very rare. One or two in past years. Majority are delighted to be on register. Want the extra support.’ (Oph10)

‘Some decline. It’s not common. Particularly because this age group, focused on learning support, very few are going to turn that down.’(Oph12)

‘I’d say 98% are quite happy to have their child certified once it’s explained to them and they know we’re not going to brand their child’s forehead with their certification, it needs that explanation.’ (ECLO3)

When parents do reject certification, ophthalmologists stated the reason was parents needed time to accept their child’s VI.

‘We would give them leaflets and information and ask them to think about it. And then see if they want to come back and discuss it again at some stage…So it would be, take the information home, think about it, discuss it next time in clinic, talk to ophthalmologist ask him or her for their opinion as well, so they can get a mixture of different voices.’ (Orth4)

It was common for health professionals to experience parents readily accepting the offer of help:

‘If they feel that it’s going to support them with regard to education and help access services then parents are very happy to get their child certified so that they can access services and do the best for their child.’(Orth3)

For children with complex needs:

‘They go for (certification), easy.’ (Oph7)

At points, ophthalmologists and QTVIs stated a small number of parents were reluctant to be certified and registered because of a so-called ‘stigma’ in being ‘registered’ or associated with SS. One QTVI observed that this happened very rarely and most ophthalmologists pointed to only one or two cases in a career.

##### Diagnosis and Age

Ophthalmologists and orthoptists are at times reluctant to certify children until they have a firm diagnosis. In typically developing children vision improves with age, therefore ophthalmologists often wait to offer certification as in some cases there may be improvements in the child’s sight as their visual system matures.

‘It depends on the condition, sometimes you wait, if it’s a condition you know, inevitably reach the standard, you certify them in infancy. If they’re ones you’re not sure about, you wait a bit and make a judgment often on the basis of what condition they’ve got.’ (Oph5)

The difficulty in measuring visual acuity and VI in babies was mentioned by most ophthalmologists but many said either orthoptists helped in this instance or that they would wait to offer certification until they could measure VA or until test results were received.

‘It can be extremely difficult to measure visual acuity in very young children, small babies. So what may appear, for example, to be a non-seeing baby at 12 weeks with something like delayed visual maturation may actually turn out to be a baby with perfectly normal sight in six weeks, or it may be much longer. I think it’s a delayed visual maturation if I think it’s a baby with much more severe visual diagnosis then it’s based on that.’ (Oph11).

Ophthalmologists that certified a number of children each year provided detailed explanations of how they decided when the time was right to offer certification.

‘Children with VI fall into two broad groups – those that have congenital, non-progressive abnormalities of the eye – albinism, congenital stage of night blindness, achromatopsia, optic nerve hyperplasia. All these things that are developmental problems they are relatively straight-forward in that the VI is not going to change. …The second group are children that have a progressive disorder, with retinal disease central vision…problems with field of vision, night blindness, and you have to make a judgement, at what point does the field get so bad that you should certify them…it’s not straight forward at all, you’re factoring in many variables …if you’ve got a child who’s got 6/36 vision they wouldn’t really meet the criteria of PS, most ophthalmologists would certify them. I think if anything with children - people tend to interpret the rules flexibility.’ (Oph5)

‘It’s not clear cut. Certain conditions where it is, there are certain where it isn’t. Some children with delayed visual maturation, where you don’t really know how much their vision will improve or to what level, so some of those it’s quite a waiting game or you’re not able to assess the child’s vision very accurately. And so you’re waiting for more accurate clinical information … But I think if it’s an uncertain diagnosis or you’re not sure with delayed visual maturation, those kind of cases you may wait.’ (Orth4)

Waiting for a diagnosis could take months or even years for some CYP, meaning ophthalmologists waited to certify and it was rarely offered at a first appointment.

‘I very rarely certify them on the first visit. Unless they are older kids and they come from other ophthalmology centres that have confirmation of poor vision and with complex general health issues…For delayed visual maturation I don’t certify on first visit. It is such complex area.’ (Oph9)

‘Hard to certify child, you need something more than one visit… At end of the day, this is quite a big thing; you cannot simply label a child as VI without something definitely solid in writing…Depends on underlying pathology, how long are you going to wait? Three months? Six months? A year? For me it’s quite difficult. It depends on individual basis and underlying aetiology of visual loss. For example cortical vision impairment from lesser A60 to birth age six years. I might wait a little bit. Optic nerve hypoplasia, from birth, I don’t think you should wait, what are you going to wait for?’ (Oph10)

The uncertainty of when to offer certification is part of an ophthalmologist’s job. This waiting period is inevitable so the key issue is whether or not CYP and their families are offered support and information whilst they wait for a diagnosis. The following ophthalmologist and some health professionals interviewed stated they were keen to offer support during this waiting period.

‘Thing is with children, sometimes actually getting reliable visual acuity is not always possible. As a result, when you feel you know the visual function is poor, for example, child has wandering eye movement that they are not fixating, even though we couldn’t get the vision, and parents know the child is blind - in those circumstances we try our best to estimate vision but sometimes I might just put down things like respond to light, even though I don’t have a visual acuity. Then I would ask for support until we give the child little more time to grow first before we go to the step of the CVI because as I said, it is a very delicate situation.’ (Oph9)

It is evident that this did not always happen – according to both ophthalmologists themselves and to parents, the offer of support / information or referrals were frequently dependent upon certification. Consultants working in Tertiary Centres stated parents often arrived at their hospitals looking for support as well as a second opinion.

‘If you have (ophthalmologists) who do not have specialist training in paediatric ophthalmology they don’t understand the pathways and the needs of the children and they don’t think to refer them to the VI services and they don’t think that a child can use an LVA and they don’t think that actually the parents do actually need help filling in the DLA Disability Living Allowance) form.’ (Oph8)

‘In a lot of units they don’t have paediatric trained ophthalmologists...it’s adult ophthalmologists seeing children so they are not aware of the benefits and impact and importance of certification. As a result they’re applying the same rule as for adults…They don’t certify, they don’t even mention it because mentioning certification is a dirty word…parents can shy away from it, it is a challenging group. If one applies the adult mentality to say ‘you have to be less than 3/60 or whatever’, you are going to wait a long, long, long time before even going to get any visual acuity out of these children.’ (Oph9)

These findings confirm research that concludes that even though most childhood visual disorders are present from infancy, there is often a ‘prolonged period of uncertainty before the final diagnosis is achieved’.(12) They also show that while ophthalmologists treating adults are often unaware of the pathways to support for their patient, there is an added complication for children, as they may be treated either by a paediatric ophthalmologist, or one who primarily works with adults. This latter group in particular, is much less likely to be aware of national policies around early intervention for children that are different to the protocols and pathways for adults, for example, the National Service Framework for Children, Young People and Maternity Services.(13)

The guidelines in **Working Together to Safeguard Children** recommend each area have a local protocol to “seek to ensure that each child and family understands the type of help offered and their own responsibilities, so as to improve the child’s outcomes”.(14)

##### Children with complex needs

An additional issue that can extend the amount of time to diagnose a CYP is that VI in children with complex needs is often under-identified and can take some time to diagnose.(12) Ophthalmologists openly referred to the difficulty of assessing and certifying children with complex needs.

‘Main reason for delaying in children with complex needs because it’s so hard to assess what their actual vision is.’ (Oph11)

Parents of children with complex needs confirmed it took some time for a diagnosis and referral for support.

‘We’d been seeing consultants since she was about 18 months… we are still trying to get a diagnosis. So it was multiple appointments with various different people…certified at four (Between 18 months and four years did daughter’s vision deteriorate?) Pretty much the same. Up until she was 3 we couldn’t decide how much she could see because she doesn’t respond to vision tests as a typical child would… She’s got multiple learning difficulties so we confirmed her hearing, vision and it’s getting results that was a problem for the professionals.’ (Par20)

Another parent felt that finding the diagnosis overshadowed their need for support.

‘In that first year, I was being hit with so much devastating news I was an absolute wreck … there is a tendency to delay the full facts of the case when parents are struggling that much. I’ve talked to professionals about this since… they don’t like to say those words until the children are around two-three years old…it gives you hope…some get better…**I needed the proper words**. When the proper words were said to me I dissolved into tears, as much as it destroyed me every time I heard them I needed them to process and evaluate the situation. I didn’t want to live in a state of hope. I needed the truth.’ (Par7)

Some ophthalmologists stated CYP with complex needs are not being referred to ophthalmology departments or offered a sight test by an appropriate professional.

‘**For us the problem is getting them seen by somebody of the ophthalmic team: that is the only reason why they get missed**… It’s difficult, we point out and say every child should be referred, every child with complex needs should have an eye assessment, that is all we can say. And we say that quite regularly.’ (Oph1)

‘Some of those children are not even seen, they assume they’ve got brain damage and can’t see anyway.’ (Oph5)

Others stated their work with multi-disciplinary teams improves the number of referrals to ophthalmology.

‘Many of our children come from multi-disciplinary teams where we supply staff to check vision for these children.’ (Oph6)

Previous research has also found that many children in special schools had not been referred for eye examinations despite having VI.(17)

##### Specialists and generalists

The research aimed to examine whether seeing a paediatric ophthalmologist would improve the likelihood of the offer of certification than with an ophthalmologist who primarily sees adults. Four of the 12 ophthalmologists interviewed did not have a paediatric specialism.

Ophthalmologists in district general hospitals (DGHs) could often go for months without certifying a child, sometimes only certifying one or two children in a year.

‘I only see children in two circumstances, one I look at premature babies and I would look at children with medical retina problems… probably in 14 years, one baby we’ve certified, he came back blind.’ (Oph12)

Research with adults (1) has shown that ophthalmologists are often uncertain about the point at which they should offer certification. However, in the current study, of the 12 ophthalmologists interviewed, those who did not see or certify children often were more likely than those with a paediatric specialism to hesitate before offering the CVI to CYP, worried it might be unnecessary or harmful.

‘Until you have a firm diagnosis it’s quite difficult to hit somebody with certifying them as blind, they find that very difficult to swallow… parents have so many other concerns about general health of child, it may be appropriate to offer certification not at the first visit. I would usually not mention it if a very sick child with parents with multiple anxieties and worries …In adults it’s so much easier to make a concrete diagnosis because they are likely to get worse and children are likely to get better.’ (Oph11)

One parent who first saw a general ophthalmologist, then moved to another area and saw a paediatric specialist commented on the different support she received.

’On a personal level (paediatric ophthalmologist) had a completely different attitude and children’s needs for support and not just from an eye health point of view but just from the bigger picture as well. Making sure (son) had support in every aspect of his life and that just made such a difference…Although (son) already certified, it was his outlook and attitude that we’d never experienced before. I think on reflection it made us realise the difference that you get between a general and a paediatric consultant.’ (Par24)

##### Time taken to complete CVI

The amount of time to complete the CVI influenced the offer of certification. One ophthalmologist spoke honestly about the inconvenience of completing a CVI during a hectic clinic and how this might influence whether or not an ophthalmologist would offer certification. This is an issue that emerged in previous research with adults.(1)

‘…in a busy clinic, sometimes, particularly if you are thinking about investigations and whatever else and focussing on diagnoses, prognosis. In the past people have not necessarily been certified that maybe should’ve been.’ (Oph12)

Seven of the 12 ophthalmologists completed the CVI themselves, 5 stated they had help from an intermediary role (e.g. ECLO) which appeared to reduce the time it takes to complete the CVI. Two areas acknowledged that doctors might overlook certification in a busy clinic so they included nurses and orthoptists into their systems to ensure all eligible patients were offered certification.

‘It doesn’t happen at more senior levels but it’s much easier to run clinics, clinics are really busy - have 2-3 minutes per patient…We have trained the nursing staff who can look into these things in much detail, even before (a patient sees an ophthalmologist), if somebody noticed 6/60 it will come with note has this patient been certified.’ (Oph2)

An ophthalmologist in a different hospital stated roles like nurses, ECLOs, save time by talking to parents about certification.

‘The ophthalmologist has to do it all himself or use orthoptists. In a busy overbooked clinic - there’s a disincentive to certify and that maybe part of it. …Patients get a quality service because of (these roles); the real key argument is they are pivotal to giving a high quality service. But they do save time... in the sense they don’t keep coming back to clinic. (Oph5)

##### Effect of one significant case

For ophthalmologists, a difficult case early in their career can have a profound effect on their approach to certification.

‘In virtually my first three months I saw a girl…she and her parents had been told by one of my predecessors that she would never see. She’s not got perfect vision but she’s 6/12 in her better seeing eye and (now) she’s a table tennis champion…a fully functioning 19 year old. What I learned from that is you’ve got to be really careful. There is a label attached to registration and I am hesitant …and it’s just made me wary, made me aware of the danger of certifying because it’s a label…. I’m just really, really scared about labelling a child and telling the parents that child’s vision is so bad we’re going to register as SI and then being wrong.’ (Oph3)

Another ophthalmologist confirmed that a single case can have a significant impact on future offers of certification.

‘Some of my colleagues have had bad experiences when they have de-registered a child, the family have involved the local MP, to complain that benefits were taken away from them. (Does this affect other colleagues, in terms of not offering certification?) Yes. 100 per cent.’ (Oph1)

#### 3.1.2 Offering the CVI and talking to parents

Our previous study (1) with adults had found that by far the most common complaint from patients was the lack of information consultants provided about C&R. Similarly, in this study many parents referred to either the complete lack or poor information provided by healthcare professionals when they were offered the CVI for their child.

‘I wasn’t really told any of the benefits, just said we’ll certify (son) as VI. I think she said something very vague like ‘it will help the support he gets when he goes to school, something really vague like that.’ (Par14)

‘It was presented to us as an option; we weren’t told we have to do this. This is what you can do. Didn’t really get much more information about what it would mean and what it might change.’ (Par6)

‘They just said ‘oh it’s got bad enough now that we can certify.’ (Par4)

Instead of receiving information from health professionals, parents themselves seek to find out what C&R means and the possible benefits but too often this results in their child or themselves missing out on important support and information and growing inequalities.

‘They didn’t explain anything at all. We left with a piece of A4 paper which had the various signatures on it, a copy of it, yellow card came later. We didn’t know if it would or wouldn’t go to other people or whether it would or wouldn’t lead to services or anything at all. We had absolutely no idea whatsoever.’ (Par13)

‘Nobody told me anything…When I got home and I had to fill in forms such as DLA, etcetera, I realised this CVI, it’s something everybody’s going to ask for. So I searched on Google, I went to the eye clinic but even the eye clinic didn’t offer it to us. They did apologise later that we weren’t put in contact with the right agencies.’ (Par19)

Whilst most parents interviewed had children certified more than a few years ago, the parent of the child most recently certified confirmed little had changed – that information provided about C&R was still negligible, and information was not forthcoming from the ophthalmologist.

**‘They didn’t really explain it to be honest with you**; they didn’t say this is what it means in terms of certification. I’ve never had it fully explained about certification versus registration either.’ (Par25)

That parents did not know what to ask for was common. One parent, whose child was certified over five years ago, was still upset with the lack of support she received at the hospital.

‘The consultant ticked the kind of support that she thinks would be good, ‘does the patient have poor physical mobility’ and she’s ticked ‘no’. And I can’t understand why she ever ticked no on that because by then we knew (son’s) mobility was poor... I don’t know why I didn’t pick up on that at the time…And then it said ‘would the patient benefit from discussions with a rehabilitation worker about practical matters such as mobility’, in the case of the child would the parent / guardian welcome advice about child development/ schooling / social interaction or parenting and she ticked no…Why would they tick no?’ (Par14)

Perhaps one of the reasons ophthalmologists and health professionals are vague is that it is difficult to explain what is on offer because SS support is so different across the country. For health care professionals advising parents on what they can expect from SS is difficult, particularly those working in Tertiary centres.

‘In some places they get quite a lot of support if you write a letter. In other places, it is truly very, very difficult.’ (Oph6)

‘From my point of view it is difficult…trying to keep up with every single borough or county is very hard…not every authority or borough works in the same way, referrals, statement…does vary. I’d love to see…a pathway, some sort of standardisation for these children to travel on so I can say with great confidence once we register this is what they’ll get - unfortunately it is very variable.’ (ECLO3)

However all ophthalmologists should be able to advise patients on the benefits of certification and registration.

##### Ways of telling

In addition to the lack of information, there is room to improve how ophthalmologists inform parents of their child’s sight condition and that their child is ready for certification.

‘(Ophthalmologist) gets very excited, as they always do when they see our eye condition, got a bit carried away, I had to tell him to slow down a little, while it sinks in a little bit...All I could see was the doctor getting excited and saying there’s something going wrong with my child eyes and there’s no telling you what it is, what that means, are they going to see?’ (Par10)

‘The first consultant we saw told us her eyes were dead in her head and they would turn black, with a load of students in the room, it was awful, awful, it was horrific…We asked to see another consultant…she’s a wonderful lady.’ (Par12)

One parent was told by letter that her child was ready to be certified.

‘I was told about his sight via a letter…The (local) ophthalmologist referred us on to (larger) hospital cause he wasn’t 100% sure, needed more tests done. So we went to hospital and they sent us a letter saying he had macular dystrophy. The final diagnosis was made via a letter in the post, then I Googled it and learnt for myself what it was ...It would’ve been good to speak to someone and say what does that entail then, what does that mean? What’s going to happen long term?’ (Par23)

For a parent with two children certified as SSI, when she asked the consultant if her second child could be certified she was told ‘it’s not done willy-nilly any more’. Both children were diagnosed under the age of one but the first child waited until age eight for certification and the second, diagnosed at six-eight weeks, was certified by the time she was one.

##### What parents want

Information is parents’ greatest need at the time of diagnosis of their child’s ophthalmic disorder.(18) The hospital and ophthalmologists in particular are consistently identified as the main sources of information for parents in the early stages (12) yet the information they provide has been labelled as ‘poor’ or ‘very poor’ by parents.(19) Parents are then desperate for specific and practical information on how best to parent a child with VI.(20) All parents who received parenting advice and information stated it was invaluable.

‘Paediatricians gave me an early journal, early childhood journal([[2]](#footnote-2)) helps you track your child’s development so I left with a very heavy folder and a space blanket…It was a bit overwhelming but it was very useful in terms of Portage and logging his development.’ (Par8)

‘(QTVI provides) parenting skills, … working with the level of vision he had, to really work with it and enhance it as much…I think we probably would’ve just thought he’s blind, that’s it. Whereas QTVI explained we need to work with the vision he has to make sure that his brain keeps working, thinking there’s still something there...We’ve done such a lot of work. So much of the work with him is with his vision, because he has CP as well. It’s massively affecting because one thing is impacted on the other. Any kind of vision we can enhance for him will make a massive difference for his life. We’ve had amazing support here, it’s been unbelievable.' (Par26)

It fell to QTVIs, not social services, to provide parenting support. There were no examples of SS providing this type of support in this study. However, most parents interviewed struggled on their own without help or looked online for advice and help on how to raise a child with VI – either because they were not referred to a QTVI or because SS did not contact them.

‘I said can I have some help with daughter, access parenting groups and they said there’s nothing we can do for you …First and foremost **nobody has given me training on how to parent a VI child**… I’m accessing and looking all the time but that would be my main thing. You have to find another parent that’s the only way really.’ (Par12)

A parent whose child was certified at age ten after a sudden medical incident did not know what to do in terms of parenting a child with VI or who to ask for help.

‘When he first came out of hospital it was very difficult 'cause we didn’t really know what we were doing. I didn’t know and still don’t to some extent don’t know how to help him, how to occupy him, things he might want to do, when he first came of out of hospital the things he used to enjoy doing, like Lego and that sort out of thing. He didn’t want to know about.’ (Par25)

For some parents, the lack of proper information and referrals had a lasting and significant impact on their lives.

‘If someone had (offered parenting advice) to me I would go out and I would look and I would find… Just knowing that, I would’ve gone looking for it. But I wasn’t even told that.’ (Par14)

This parent, told by a paediatric ophthalmologist to ‘treat him like a normal baby’ still felt guilt over the advice she was given for her now ten year old child, certified when he was under one year.

‘Looking back now I do feel quite bad that probably I didn’t do more for him as a baby...The doctor at \*\*\* just said to me just treat him like a normal baby. Just carry on exactly like you are…if they’d certified him and I had had proper advice they might’ve said to do as much as you can to stimulate him. She said just treat him like a normal baby. And really it never sank it at all then that he was VI, they told me that. I went away, of course I was upset but I just didn’t really believe, for probably a couple of years. It just didn’t sink in. I think I was in a bit of denial for a long time. If he had been certified and I had spoken to a QTVI earlier and been given more advice it would’ve, I don’t know if could’ve done more or not. I don’t know. I had nothing like (parenting advice). Nothing at all.’ (Par14)

Of the four families discussed in this section only one was offered support before their children were certified, the rest were not offered support until their child was certified and registered. In some cases this was years after diagnosis and despite the fact that babies and young children with vision impairment require specialist intervention as early as possible to support their development.

However parents immediately sought information online – often desperate for information such as parenting and also basic information on what certification and registration meant.

‘We researched avidly. She is now in VI school we’ve been quite proactive in ensuring she gets the best opportunities and chances.’ (Par3)

‘Until you start talking to other parents and then they say did you know about this, did you know there’s that? It’s passed on through word of mouth or through FB pages. It’s not really well advertised. You really need to go hunting for everything you need.’ (Par18)

Health and education professionals also noted how frequently parents looked online for information.

‘Parents are very good at looking things up on the internet; they come up with lots of information if we can access this support if they are registered. I think more parents are proactive these days.’ (Orth6)

When professionals referred parents to information online it was appreciated.

‘I think (QTVI) she pointed us towards some websites but we can look it up and find information, found ourselves. Point in right directions, QTVIs have been brilliant, fantastic.’ (Par21)

However, researching on the internet cannot entirely replace apposite written information – parents wanted this in addition to looking online. Whilst four of the five hospital areas studied said they provided written material the majority of parents, 21, did not receive any written material. (Parents had experiences of 17 different hospitals in England.) They wanted written information about the eye conditions, treatment and prognosis and about accessing services and benefits.(21) As many parents are overwhelmed at the time of certification, written information enables them to reflect on information after the appointment.

‘It can all come as a shock in the first instance, to process it all, everything’s spinning around in your head. So if you’re given something written that says, ‘your child’s been diagnosed as VI, this is the sort of things you could do that would really help you and your family going forward’ just a few points saying it’s really important children are stimulated.’ (Par14)

Parents also stated they want simple, practical information.

‘I’ve got reports from (hospital). It’s always about his eye health and how he sees, his development, but on the practical side, no, nothing… Tips and advice from other people who’ve been through it, like a booklet, written by parents for parents.’ (Par18)

It was important for many that the written information was offered when CYP were certified and registered, so parents would know the processes as well as what was on offer.

‘Something there for parents at the point of diagnosis and certification.’ (Par8)

‘I think when they actually do the certification (when) you get the Certificate, it would be nice to get more detail of what you’re entitled to, written down. Like a leaflet or something. A lot of the times when you’re in all these appointments, there’s a lot of talk, talk, talk. Things can go a little over your head because there’s a lot of information to take in at one time.’ (Par20)

Parents who received written information valued it greatly.

‘When (son) was first diagnosed I got a book from the RNIB you’ve got a child with VI, it’s the most useful thing in the world, I’ve still got it. Something like that with more addresses in would be useful, just something you can go to that would list all the links.’ (Par16)

Information provision is an ongoing process and not a single event or something that occurs only in the early stages of diagnosis. Each appointment is an opportunity to offer a CYP and their family support and information –- obtaining information about education and social care services is a priority for parents.(22)

##### ECLO/Intermediary roles

The role of intermediaries / key workers – such as specialist nurses, Eye Clinic Liaison Officers (ECLOs) and Family Support Unit roles have positive effects during the C&R processes for CYP and their families but only for those families who are referred. These professionals provided practical and emotional support and referrals to local authority VI teams. Generally ophthalmologists did not have the time or the correct information to provide this kind of support so these roles complimented the ophthalmologist role.(12,18)

They offered detailed and accurate support and information about what it meant to be certified and registered.

‘What we do if a child is certified with VI we are now ringing the parents up with telephone consultation clinic, where we will talk about certification…We make sure that they’ve been referred to VI services and local services, access groups and things, and local Blind Society…We have a CD, lots of information leaflets on which we can pass on to parents and patients…(CD has) things to do with DLA, support groups, leaflets on particular diagnosis.’ (Orth3)

‘Talk things through with parents and we give them information, leaflets we have, give websites to look at, also have information on conditions, do look at RNIB, tell patients to look at, especially criteria for certification, sometimes we print off information so they can go away and look at it, so they know what the benefits are.’ (ECLO2)

Parents who attended children’s hospitals, where most have roles such as ECLOs or Family Support Units, very much valued the information and support they offered.

‘When we had hospital appointments, we were up there quite a bit in the first few months… (they) would sit in on the appointments that we had…she was a really nice lady, nice bedside manner, the information they first gave us, it was really helpful and it was nice to know someone was…We would’ve felt really isolated and not had a clue basically. I don’t really know what we would’ve done.’ (Par22)

However, even when these personnel were in hospitals, referring to these intermediary roles was not consistent, instead it was a subjective decision made by ophthalmologists.

‘If doctors think patients would benefit from seeing us, they refer, if child struggling at school with vision, they can come and see us, we refer to VI service.’ (ECLO2)

‘We were given details of (ECLO) but no one ever spoke to us.’ (Par6)

Many other parents were very disappointed when children’s hospitals/ Centres of Excellence failed to provide support or information through these roles – when they were not referred. One parent was not told of the purpose of C&R even though they saw orthoptists, consultants and optometrists from her child’s birth at one of these Centres of Excellence.

‘I was supposed to get a journal - from birth up to about five, about certain things you can do with blind children to help them. I never received it and they promised me it…every time I went up there I would ask about his folder and they said, yes, it’s being sent to you, I still haven’t got it…what I always heard, oh yes, at least my child is in good hands, he’s at one of the greatest hospitals, but when I had dealings with them myself, I was like, hmm, maybe not.’(Par18)

At another children’s eye clinic parents complained of:

‘A frustrating day at hospital…very, very long day, one clinic with one consultant, adults and children, there from 9(am) to 5 (am) with a little one.’(Par10)

Support in another children’s hospital in the eye clinic was described as ‘non-existent’.(Par19)

Despite the inconsistencies of the offer of this type of support, ophthalmologists stated these intermediary roles could potentially solve many of the problems faced by parents of CYP with severe VI in providing timely information and support.

‘I think ECLOs are one of the things that would really help transform care for children with VI over the years.’(Oph5)

An ophthalmologist confirmed these roles improved patient experiences:

‘Families get a lot more time than I could spend with them. They definitely get a better quality of service. They might spend an hour with family, I can’t spend an hour.’ (Oph4)

In one area an orthoptist who used to work with ECLOs saw them as invaluable in term of supporting CYP during the C&R processes.

‘When I was in \*\* they did have (an ECLO), someone designated when you give them the bad news. There was somebody in the department to talk to, we haven’t got anyone like that here…That’s why we try to give them information. We copy them in on letters we write about them. What we can do is tell them to look at our website which has links, like to nystagmus, on hospital website. On there, we’ve got links to different organisations, RNIB.’ (Orth5)

#### 3.1.3 Completing the Certificate of Vision Impairment

An important factor that delays sending the CVI out of the hospital was also found in the adult C&R processes: batching CVIs. As with adults, a simple way of delaying access to support is when CVIs sit on the desks of either ophthalmologists or their administrators, waiting to be completed and posted to social services. **Batching is an entirely unnecessary delay** resulting in unnecessary waiting and anxiety for parents and their children.(1)

‘Problem we’ve got is the hospital, they have a tendency to save them up and send them in batches. Three or four months back, they’ve collected a pile and sent them.’ (SS11)

‘(Ophthalmologist) does (CVIs) in batches, that’s the trouble. Suddenly you get eight or nine at once because that’s when he does his admin. I understand, his clinics are full, he’s not here every day. I’m not quite sure what the answer is.’ (ECLO1)

One area identified that CVIs sitting on desks was a problem and addressed the issue:

‘Year or so back found CVIs for children coming late, weren’t many of them, quite worrying so we … Sitting on secretary’s desk…months, six months…I have close links with social services manager, we talk quite frequently, liaise a lot… So we got together with various people in the chain – consultant, orthoptists, child development centre and looked at the whole process and how to speed it up and make sure families got support and information earlier.’ (Nur1)

However, SS and QTVI in this second area stated they still received CVIs in batches:

‘Sometimes you get a whole lot, consultants’ secretaries still batch, even though they shouldn’t and sometimes we don’t get any for a while... The one we saw yesterday was certified as severely sight impaired a few weeks back, well I still haven’t received that paperwork…So I can’t access things like car badge or DLA mobility, registration card, TV license but Mum knows about them and knows they are in the pipeline.’ (SS3)

Parents reported that batching and administrative errors can lead to substantial delays in support for CYP.

‘The paediatrician said we’ll refer him now but they didn’t, (CVI) got lost in the system and it’s only because I chased it that we were referred... The whole system flopped from the beginning … (CVI) lost three times, twice in hospital and once in education.’ (Par10)

### 3.2 The Registration Process

Professionals from seven social service departments were interviewed and described six different processes of registration – revealing the difficulty of establishing a pattern in service provision and expectations of what CYP and their families might experience after certification.

#### 3.2.1 Who receives the CVI

In two areas the CVI is received by adult SS who refer CYP to their own staff and a QTVI. The QTVIs in these areas confirmed this process. In two other areas the children’s SS team receive the CVI and then refer to the QTVI. In the areas that receive the CVI via adult SS both children’s SS teams stated they wanted to receive them directly from the hospital to avoid delays in contacting parents.

‘I don’t understand why the people who give CVIs don’t send them to children’s services. I just don’t understand that. Or at least informing us. Why it has to come through a third party I don’t understand that at all.’ (SS8)

In the remaining three areas the registration process is less consistent. In one area a local charity receives the CVIs, a new process which also involves seconding a member of SS staff one day a week to work with CYP in a rehabilitation role. The local charity sends the CVI to the QTVI, hoping to improve the previous practice as they stated the adult SS ‘wasn’t sending them on’ to education.

In two areas the QTVI receives the CVIs directly from hospitals; SS have a minor role in the registration process and maintaining the register.

#### Case Study: ‘What is a CVI?’

A consultant with over 10 years’ experience who regularly certified children was referred a patient from outside their catchment. The child had abnormal eye sight in both eyes. In the first appointment the consultant referred the child to the local QTVI and in the following appointment the consultant completed with CVI with the parents. As usual, the medical secretaries then sent the CVI to the relevant person in Local Authority however, within a week they were contacted by ‘very anxious’ social worker. The social worker stated they had never before seen a CVI and asked ‘what is a CVI form?’.

In further discussions with the consultant it was apparent the social worker did not understand the purpose or information included on the CVI. In Part 3 under the section ‘Other relevant factors about the Patient’ the consultant’s comments of the child ‘failing to thrive’ due to an undiagnosed syndrome were interpreted by the social worker as a safe guarding concern and they believed the purpose of the CVI was to highlight a child neglect case. The consultant explained the purpose and process of the CVI but the social worker remained unaware of how to proceed with the CVI. Instead, medical secretaries were left to unravel the CVI process in the LA concerned:

‘(Social worker) did not know within their own department who was dealing with the CVI registration process…we had to chase around…we were passed from one person to another…no one is responsible for the CVI and no one knows what to do with the CVI form’. (Oph8)

After several weeks the medical secretaries identified who they believed to be the person responsible for processing CVIs for children within the LA but remain unconvinced this is the correct person as some parents from across this region complain they have never received a registration card or offered support from social care.

#### 3.2.2 SS and support

In three of the seven sites where SS professionals were interviewed **there was total absence of clarity of the referral route or provision of support for parents of VI children**. On the whole, if SS offered any support at all, it was a ‘**light touch’** (SS9). The six social service managers described the type of support they offered, emphasising their role in signposting and providing information about local support.

‘Don’t do anything official, like any home visit…there is supposed to be a transference of information within 2-3 weeks of the family getting the CVI…at the moment there isn’t anything formal in place further to a meeting with (rehab officer).’ (SS8)

‘Nothing in particular, we would be sign-posting.’ (SS6)

One parent observed, in relation to the timing of certification and registration:

‘I wish I’d known about it before. Because we could’ve got Disability Living Allowance earlier. We could’ve got the help from SS earlier.’ (Par13)

When SS did offer support, it was highly valued. One parent described the substantial support her local SS provided to help re-house her family after her toddler was certified as SI.

‘(SS) came to see us and we were living in a flat at the time, lots of steps and things and electric fence next door. It wasn’t something I was aware he could help with but he suggested he wrote to housing department for us which he did and we got rehoused about four months later. That was a big help…They followed up, a few months later with a phone call to see if there was anything we wanted. Leaflets about lighting and things like that, around the home. RNIB catalogue, things we might be able to buy to help him.’ (Par5)

Section 3.3 discusses in more detail, the benefits of SS support to those parents who did receive it. But more formal support from SS was rare – interviews with both parents and SS professionals confirmed this. Parents said SS usually made only a vague offer of support. However, this vagueness is unhelpful; parents needed to be told what was on offer not only that SS were ‘there’.

‘I had a call from SS and all they said was well my child is disabled, they’re just letting us know they are there if we need anything but nothing else was mentioned. They just said if you need us, call us. (Tell you what was on offer?) No. if you need us, we’re here…They didn’t tell us about any services, it was just a quick call, then done. Not much information.’(Par18)

Parents do not know what to ask SS for so few thought to approach them for support.

‘It wasn’t that I’d approached them and they’d refused me anything it was just I hadn’t any experience…I didn’t know what to expect from them, nothing was explained to me… If you don’t know what you’re asking for, you can’t ask for it.’(Par24)

**All health professionals** (including paediatric ophthalmologists) interviewed also certified adults so most had experiences of SS being very active in providing support to adults and could not understand why SS did not get more involved in the provision of support to CYP.

‘It is a continuing frustration, within adult services we have very good links…Because education service is so good the SS side of it tends to hand over a lot of that to the VI team and the VI team do quite a lot of that work.’ (Oph8)

In such a situation, while they may receive good early years and education support for their child, parents are denied the wider support traditionally provided by SS.

QTVIs were similarly **unclear about the role of SS in the C&R processes.**

‘We need some clarity about what our children’s social workers are offering - they tend to only really get involved when there are safe-guarding issues rather than on-going social care, possibly when there’s benefits and direct payments. We haven’t had a history of very strong working links between the teachers and SC so I’m not really clear what they’re providing actually to be perfectly honest.’ (QTVI3)

Instead, most often parents received support from QTVIs, as will be explored in the following section.

#### 3.2.3 The role of QTVIs in certification and registration

An additional inconsistency in the registration process is that some QTVIs recommended C&R whilst others did not wish to get involved. Half of the QTVIs interviewed said they would advise and explain to parents about the registration process:

‘If you have a child referred through medical route who we feel should be certified, we would then go back to our contact in the hospital and say have you not considered this child should be certified?’ (QTVI8)

Half of QTVIs did not regard it as their responsibility but nonetheless still provided information about registration.

‘It’s not really for us to say if they should be registered because their vision might change. Occasionally the readings they’ve got in clinic have been very different to what my perception or parents’ perception is. In which case we say when you go to clinic next time, tell the person who’s doing the eye tests what your feelings are and what we’ve seen on the home visits and how your child is functioning.’ (QTVI1)

‘I’m not aware of what the systems are. We haven’t historically promoted certification.’ (QTVI3)

A parent who waited three years from diagnosis for her daughter to be certified wondered why the QTVI didn’t suggest certification to help her child access more support.

‘Now that I’m talking to you all sorts of alarm bells going off in my head and I’m thinking why didn’t the QTVI mention certification?’ (Par13)

#### 3.2.4 Accuracy of registers

The Care Act 2014 (section 77) places a duty on local authorities to maintain registers of visually impaired people: maintaining a register must include reviewing and updating it.(23)

One purpose of the registers is to enable local areas to accurately plan services based on local prevalence rates and population data. That the registers might not be accurate was picked up by most QTVIs - who offer the bulk of support to CYP with VI.

‘I’ve thought about this a lot. The purpose to me, the problem is not everybody’s registered. From a local authority point of view, for forward planning it’s important but not everyone’s registered and don’t have to be. It’s patchy information that you have. If everyone was registered it would be great for planning, make provisions for the future.’ (QTVI4)

With local authorities under pressure to reduce spending – **registers could provide valuable information on the number of children with a severe VI in need of high level, specialist support** and to use these numbers as a minimum in terms of the level of need in an area.

‘If registration is taken away that cohort of children is very difficult to identify.’ (QTVI7)

‘It helps us (with) provision mapping, it definitely helps us to defend our levels of staffing, if we’ve got those CVIs, a comprehensive accurate register - it would definitely help us to make a case to defend our staffing levels.’(QTVI5)

However interviews revealed that many councils are not reviewing or updating the registers for CYP. That no new registrations were issued for CYP in many areas in England in 2014 is worrying, given the importance of holding accurate data to enable effective service planning for this group of children who require high levels of specialist support. There seems to be confusion about which part of SS the certificate goes to - the children’s team or the adult team.

Of the seven social care departments studied, the CYP’s VI register was held by:

* 4 areas - Social Services
* 1 area – Local charity
* 1 area – QTVI
* 1 area – unknown

In addition to the confusion over who held the register - in some LAs the definitive register of CYP could not be found. Of the seven social care departments studied, two local authorities did not know where the definitive register of CYP was physically located nor could they find a person who knew where it could be found.

‘Have searched and searched who keeps (CVIs), can’t find who keeps them here…Have spent hours trying to find out… it’s just not right, we don’t know who keeps them, nobody we knows , we’ve been everywhere and nobody seems to know.’ (QTVI4)

Another two LAs had multiple registration lists and could not identify which register was accurate. In one LA where SS contracted out updating and maintaining the register, the local charity was still waiting for the definitive register to be delivered - months after they should have started work on it.

‘They can’t find the definitive record …I can’t tell you how chaotic the Council is…(The) Council ran down the service before they put (the register) out to tender.’ (SS4)

For a number of years it appears that many local authorities have not updated or maintained their registers.

‘(How many children are registered?) Not sure, don’t have database, are developing. Think [we] have around 30.’ (SS10)

‘I’m in the process, because we’ve discussing this with social services, in the process of trying to get an accurate picture of how many CVIs we have…because we haven’t had a consistent approach … prompted by a FOI request …from RNIB… when we looked at the numbers that we pulled out of our database, it was really inaccurate, it was a small number and we know we have far, far more children who are registered or who have a CVI.’ (QTVI5)

In most areas CYP were not automatically transferred to the adult register.

‘I had not done any transition into adult service yet. I have tried to find out how you transition but nobody seems to know. I’ve been in touch with the adult team and they say ‘I don’t’ know’. (SS14)

‘Another protocol being rewritten as we speak.’ (SS6)

This bureaucratic delay is entirely unnecessary - three areas stated they had transition teams in Social Services to ensure support is seamless.

‘There were transition workers…we’re the same team, so you don’t leave our team…we work from cradle to grave.’ (SS3)

‘We have a transition team, referred when 14. We will meet with child and parent to say you are eligible for adult services/care. Once CYP reach 17 or 17 and a half the transition team start overview assessment and an adult social care assessment to see whether they meet the criteria for adult services.’ (SS10)

One SS manager stated updating the registers did not occur because of staff shortages.

‘I know why are numbers are down in some respect. (We) had a lot of children on their database who are now over 25 and they haven’t had a manager, hasn’t been sorted out.’ (SS8)

The value of the registers was unclear for two SS managers:

‘Sometimes I feel it’s a financial benefit. I’m not too sure what else. Financial benefit opens up loads of doors, so that’s a good thing. I’m not sure what else.’ (SS8)

‘To be honest, I don’t know (the purpose).’ (SS6)

Not being aware of the purpose of registers might lead a manager not to prioritise the task of maintaining and updating it.

One SS manager readily agreed the registers were not reflecting need:

‘Figures generally for children and adults with VI are confusing me because our numbers generally are down and yet statistics are telling me there’s 20% more VI children and adults, I don’t really understand it. Our numbers are definitely down, definitely.’ (SS8)

And one QTVI suggested another reason why registers did not reflect need or eligibility for access to specialist support.

‘Each borough might have a different criteria, it might be the element in question, who’s judging them, what judged on. Very easy for authority to raise the criteria because we can’t afford to keep paying out in statements.’ (QTVI6)

That some local authorities are not collecting relevant information or maintaining registers contradicts recent guidance issued from the Department for Education and the Department of Health which states local authorities:

‘…should ensure that registers of disabled children and young people, and particularly details of those with a vision or hearing impairment, are kept accurate and up to date, as such low-incidence needs are particularly difficult to plan for from national data sets.’(24)

In this context, the Special Educational Needs and Disability (SEND) Code of Practice defines ‘should’ as meaning, ‘the guidance…must be considered and that those who must have regard to it will be expected to explain any departure from it’. The Code of Practice does not state registers ‘must’ be provided – which would make it a statutory requirement, although LAs would need to have a very good reason for not maintaining them.(24)

#### 3.3 The value of C&R: Prompting and ensuring support, empowering parents

Regardless of when the actual support appears, CYP and their parents were grateful for the specialist support they received as a result of being referred. Parents repeatedly stated they agreed to be certified and registered solely because of the support – direct or indirect - it prompted.

‘It was registration that triggered SS involvement, once registration went through suddenly SS appeared and nobody had told me…I’m overjoyed I have a social worker, we’ve had the most wonderful social worker, really helped. She came to the house, did a really good assessment, she looked at the wider picture…That’s been, for us, an absolute godsend.’ (Par13)

‘It’s helped in terms of making things clearer in terms of DLA, with parking, it has been useful in terms of just being able to say this is the situation.’ (Par2)

Six of the seven parents interviewed who had children with complex needs and VI said C&R helped them secure additional support.

‘Respite was my important thing. Having a child that was registered blind was something that gave me an extra five points – of how hard was my child to manage…When you know that your support package is based on how many points you score, you want as many points as possible.’ (Par7)

C&R also played a role in helping some parents and others to acknowledge the serious nature of their child’s VI. For one parent with a five year old certified as SSI, the CVI provided them with evidence of need.

‘Registration has helped – financial support in terms of DLA. You can’t see that she’s blind so the registration helps to prove and identify her visual impairment. People don’t trust us, she looks normal; it’s a piece of paper that proves she needs support.’ (Par19)

21 of the 26 parents readily agreed C&R helped them, with five stating it helped them secure access to education.

Similarly, QTVIs and SS stated that in their experience, few parents rejected certification and registration as it could bring several benefits:

‘Most parents want recognition (child) has SI and can be certified. It allows them to apply for higher Disability Living Allowance, it supports the parent, accessing services. If they want to be re-housed to more appropriate accommodation.’ (SS10)

#### Case study – Changing lives when C&R ‘works’

In the 26 interviews with parents there were a limited number of examples of excellent care and practice. One parent participated in the research as she was anxious to show good practice did exist.

‘That’s the reason I wanted to do this (interview), to say how well we have been treated…We’re very lucky, very fortunate because we know that it’s not always the case. You know other people have to fight so hard and we were lucky, probably not the right word – fortunate - it’s how it should be.’

Their child was certified as SSI in his first month after they were referred to a Tertiary hospital immediately after he was born. Despite a diagnosis taking a few years, they received support from the first appointment at the Tertiary hospital. At the first appointment the ophthalmologist and intermediary staff member discussed certification and spent time with the family explaining ‘the services we could get’ and ‘about the tests (ophthalmologist) had done and the results, conclusions they’d come to’.

‘(Intermediary) gave us the Certificate and basically said if there was anything we needed to know and gave us some literature. Books, things we could do.’

Five years later they still remembered this appointment being overwhelming but on reflection, believed it was the right time to hear this information.

‘Because (son) was so young it gave us a really good chance to - I don’t want to say take in - everything was set in place then, so quickly. To be able to get him involved in Portage, everything happened really quickly and I think that was a good thing.’

The most valuable element of the C&R processes was the prompt referral to a Portage worker, who initially visited the house each week.

‘We had Portage from when he was six months old and they were amazing. They gave our son the best start…We just did not have a clue. The time that they spent with him, teaching him to sit up and use his hands, all just the stuff that gave him a really good start. They were able to talk to us as well. You know, so we could meet other parents, they were just so good, not just for [our] son, but us as a family as well…For us, it was the best start we could’ve hoped for, having them involved.’

A QTVI became involved when Portage no longer offered relevant support.

‘He started at the local nursery a couple of times a week ‘cause we wanted him to be able to socialise with other children.’

The support they received from SS was more confusing and they were unable to identify exactly what was offered and when, but it was not of concern as they received so much support from the Portage worker and the QTVI.

‘We received the Certificate but we thought we were getting a card, something to put in your purse, so I contacted Social Services to see about that and then a lady did come out. It was cross wires really. We went through everything and she said do you want respite and all that stuff and we didn’t need that.’

The parents most valued the early intervention and early provision of support prompted by the offer of C&R.

‘I really feel like if it wasn’t for (Portage), (son) wouldn’t have had the start. I don’t think we could’ve given him the best start. Even all the doctors and everyone at (Tertiary Hospital)...We didn’t feel like we were just a number, they took the time to sit with us and talk it through.’

### 3.4 The problem: Simultaneous diagnosis and referral

The aim of C&R is to initiate a reliable route to support from social care services. This is consistent with the Royal College of Ophthalmologists guidance, which lists three purposes of ophthalmic services for children, one of which is to maximise “function in individuals with permanent visual impairment - e.g. provision of low vision aids for children with congenital eye anomalies or habilitation/rehabilitation programmes”.(25) All 12 ophthalmologists interviewed were aware of this purpose and all also stated they often referred CYP for support before then - when CYP and their parents appeared to need it, although the referral was more often to the specialist education service than to social care.

All ophthalmologists stated they referred CYP to education support before they were eligible for certification – or that systems were in place, such as seeing orthoptists, to ensure support was offered.

‘We’re also going to be referring people who aren’t certified - from that point of view they are equally going to have access to learning support.’ (Oph12)

‘If a child needs certification, if they’ve got poor visual responses you don’t need them reading down an acuity test. There’s always a way to assess vision well enough to be able to work out and if you know what the underlying diagnosis is, if you put the two together then you can make a very reasoned judgment in terms of what the right approach to take. Never really found that a problem.’ (Oph4)

‘I would question whether it makes material difference to that child or the parents if you hang fire. I don’t leap in and certify until I absolutely know where they are going to end up. And I’m still going to do all the other things that I would do for them, referral for low vision aids, for to teaching service, specialist optometry and so on. It’s on my list but I wouldn’t say I, I personally don’t leap in and certify early on. I do certify when I know, if I know that child, there might be some situations where you do it without thinking, do it very quickly.’ (Oph3)

In one area the ophthalmologist referred to a pathway for support that was independent of diagnosis. However, **this was the only reference to an official pathway for support independent of issuing a CVI.**

‘The urgency for me is to get the teachers for the VI involved. **That’s a separate referral pathway**. If we are not sure the criteria for certification are fulfilled, but we are quite certain that the child could do with some support, then we will refer them to the teachers for VI so that for all practical purposes they get the support they need…Anybody in the team can refer.’ (Oph1)

It is evident however, that this did not always happen – according to both ophthalmologists themselves and to parents, referral for support to education and/or SS was frequently dependent upon certification. A mother who saw both orthoptists and ophthalmologists was not offered support without a diagnosis:

‘Her vision’s been same, she’s needed help from very start. I really don’t know why they didn’t give us registration earlier.’ (Par20)

The period around diagnosis is critical for parents to understand and accept their child’s sight loss and the implications of their child’s special needs.(12) Evidence consistently finds parents want medical professionals to share information with them about their child from a very early stage, before a diagnosis is found.(26) The lack of diagnosis can present a serious obstacle to parents being referred, receiving support and information from education and social services and accepting their child’s VI. Many parents state delays in diagnosis lead to high levels of stress.(27)

‘I think the hardest thing was because there wasn’t an absolute diagnosis… That’s why I was in a denial about it. Not that I thought they were wrong, it just didn’t seem very real to be told you’ve got a baby who is VI but you don’t know why. And you think maybe it’s not that bad, maybe…no one really said well, whatever the reason, he is and we should be doing this, that and the other. Looking back now should’ve happened, it didn’t matter what the reason was.’ (Par14)

It is during this crucial period of uncertainty that parents want support and information about how best to parent their child with a VI. One rehabilitation worker spoke of parents’ experiences waiting for support during the diagnosis period.

‘We’ve had that where (ophthalmologist) won’t certify…(and) wait to see if child gets better. I think hospital should be working on the negative - the child might get better, but might get worse… (parents) tell me about battles they’ve had to get the child certified.’ (SS14)

QTVIs confirmed that some children go without support because they are not referred as ophthalmologists wait to see if vision improves.

‘If we’ve got a child in school - even if it’s a relatively temporary or fluctuating thing – they are still going to be having difficulties accessing the curriculum and ultimately our reason for existing is inclusion and access to curriculum…. if they’re treating someone for eye condition and they expect the outcome to be that child’s vision will return to normal then (ophthalmologists) wouldn’t regard them as being PS or SSI even if for a while they might be. We would.’ (QTVI5)

Under special educational needs and disability (SEND) legislation, a child or young person’s entitlement to specialist educational support is entirely independent of the C&R process. QTVIs repeatedly stated children do not need to be certified or registered in order to receive educational support – it appears that the reason **CYP do not receive educational support is because they are not referred by health professionals**.

‘(Registration) doesn’t open doors [to QTVIs]…we can offer all the resources and things whether they are registered or not.’ (QTVI2)

‘Registration and certification - we keep a record of it, it’s not part of our criteria nor is having a statement - it’s having a diagnosis.’ (QTVI5)

‘It’s the access to the curriculum we’re more interested in rather than the registration.’ (QTVI1)

Two-thirds of parents interviewed stated they only received support upon issue of the CVI. For 18 of the 26 parents certification prompted support; they did not receive any before being certified. These parents frequently discussed how ophthalmologists emphasised diagnosis and delayed the offer of support.

‘They really didn’t do a lot before (certification), that’s what I’m angry about, those years before school, more wasn’t done. Now when I look online and stuff you see all of these nursery schools for VI children and afternoon sessions and play sessions. There was none of that, I didn’t know about any of that.’ (Par14)

‘(Ophthalmologist) said to me he hoped (child’s vision) would be good enough not to certify but actually at that point maybe we should’ve been put in touch with somebody. Cause (son) had to start all of these tactile skills very late on…Looking back I should’ve been a bit more ‘shouldn’t we not certify him anyway?’ I think at the time it was almost like we were following instructions.’(Par17)

Of the seven parents who received support before certification, four children had complex needs.(28) A small number of parents received no support upon their child being certified and registered and another group did not receive support (from education or social care) until they repeatedly requested it.

In some cases parents experienced delays in accessing support even after certification. Where the delays were was not always clear– was the CVI left in the hospital or did the referral to education simply not happen? One parent with a child with complex needs who was certified under the age of one waited two years for any type of support and information to be offered.

‘We were seeing orthoptists all the time ‘cause he was dealing with squint and patching. And seeing the consultant who was checking his vision. We’d go every six months for an appointment, it was just monitoring, nothing was being done, they never said they could do anything for his vision…I really was in the dark about it, looking back, I was so naïve. It’s because I didn’t I have experience of VI at all at that stage and he was so young and he’s got an older sister and I was just busy getting on with day to day...There was so much going on. And we really weren’t getting a lot of advice.’ (Par14)

There were numerous instances of inconsistent referrals - complaints from parents, QTVIs and SS. There were examples of the referral system completely failing – leaving CYP with vision impairment without any support until a parent found it themselves. It was rare for parents not to be contacted by either a QTVI or SS, but it did happen.

‘I didn’t hear about anything, a neighbour told me about a centre so I started going there, run by local charity for children with sight impairment …it was via a neighbour rather than any information we were given.’ (Par2)

‘I chased it all up myself. Managed to get him support from a Portage worker who we now see regularly… registration got lost, didn’t put through, then did go through and sat on someone’s desk in education department for a long, long time.’ (Par10)

#### Case study – The wait for diagnosis and support

One parent of a child diagnosed with idiopathic nystagmus at age nine months waited until he was three to be certified and for the offer of support and information.

‘I think they were waiting until he got to a certain age for it to be stable and to say his visual acuity is definitely 6/24.’

What prompted certification after more than two years was the child’s participation in a research project – and the research staff recommendation.

‘We went to (another hospital) to take part in research project… (to) discover he had presumed ocular albinism, that changed everything then. Back to our hospital, saw consultant who did certification there and then. It was all a bit strange. All of a sudden they certified him.’

One reason for the delay in the offer of certification was they never saw the consultant, but instead ‘always (saw) orthoptist’. Before certification they asked for their child to be certified but their requests were ignored.

‘We pushed, we had to keep asking, keep asking...It was muted initially, they said initially, at some point, he can be certified as partially sighted if you want to do that. I think they presented it as an option because they say some parents don’t choose to do that for whatever reason…We had to keep pushing at every appointment …it wasn’t that they weren’t listening but it didn’t happen until we got to the end point, got the ocular eye diagnosis…we were very clear we wanted it done.’

The delay in the offer of certification was upsetting, partly because they were not offered support until their child was diagnosed.

‘I was very upset about it 'cause I felt like they hadn’t looked into anything when they could have. But we just wanted him certified… Three months goes by and you go back and nothing’s changed. Before you know it a year’s gone and nothing’s happened, it’s really frustrating.’

During the wait for the CVI to be issued their child was not referred to education - the referral occurred when the mother met a QTVI teacher by chance. After registration SS visited after five months and the rehabilitation officer eight months after. The wait for support was entirely unnecessary – this family wanted help earlier.

‘Personally I can’t imagine (C&R) can be negative because you don’t wear a big badge around your neck saying ‘I am partially sighted’, it’s just one of those things that opens doors to help. I don’t know how it can be negative to get your child the help they need, that’s effectively what you’re doing. It’s a disability - you wouldn’t think that with any other disability would you?’

### 3.5 The Referral to Specialist Support

Being registered is a voluntary choice for CYP - it is not a pre-requisite for support from social services or education. However, as indicated in the previous section, for many CYP the referral to support only occurs after the CVI is offered.

#### 3.5.1 Health Education: The primary referral route

The most common referral route to specialist support for CYP with a severe VI is a direct referral from health to education (usually via letter). Education Health and Care Plans will require a health body, when they detect a CYP to have a VI, to ‘inform the child's parents and bring the child to the attention of the appropriate local authority’.(29)

In six of the seven LAs where VI education professionals were interviewed, the services received referrals directly from hospitals. Even if there was a direct referral process between health and education, it did not always work. In one area with no new registrations in the year ending March 31 2014,([[3]](#footnote-3)) the QTVI stated the referral process was ‘complicated’ and could not provide a clear explanation of how CYP were referred.

In all LAs and in all interviews with parents, the lead professional supporting children came from education rather than social care (where adults received their support). Only one of the eight local authorities studied (with an active rehabilitation Sensory Service team) stated they shared leadership in the provision of support for children with VI.

‘(Who leads in the support – you or education?) Depends on what you want, if it’s education, contact them, anything else, contact us. If there’s mobility issues, contact us.’ (SS3)

Once a referral from the hospital is received, QTVIs are quick to contact parents – the first contact is usually made within a few weeks, usually by telephone.

#### 3.5.2 Good practice: Direct referrals

To encourage prompt and consistent referrals, two areas created referral forms to directly refer from health to education as children were getting lost in systems and referrals weren’t happening fast enough.

‘We get parents to sign a consent form to say they are happy to share information so we can liaise quite easily.’ (Orth3)

The DH already promotes a process for direct referral from health professionals to others who can offer support, based on a Referral of Visual Impairment (RVI) form. This referral does not require the patient to be certified and registered.

#### 3.5.3 Support from local authority VI teams

Parents consistently and emphatically stated that QTVIs were the most valuable source of help they received in parenting their child. While ECLOs (and in some cases, nurses) had a crucial role in initial support including emotional support, and in signposting parents to education and SS, it was the QTVI who then took on the role of key worker.QTVIs provided support and information on education, parenting skills, funding/welfare, social opportunities and emotional support.

‘I can’t fault her. She was a godsend, she was so helpful and useful… She seemed to know what she was talking about, she gave us some hope, she came to see my son every couple of weeks, invited us to VI play group and telling us about events.’ (Par18)

‘The QTVI has basically been the source of all our support and she has pointed us in the direction and helped us in pretty much everything… Everything we’ve had has come through QTVI and she’s been phenomenal. But we haven’t had any other support.’ (Par17)

QTVIs hold a specialist mandatory qualification based on a wide range of learning outcomes set out in a national specification.(30) Because of the specialist training and the skills QTVIs possess, they are ‘better able to raise the achievement of pupils with sensory impairment, not only their academic attainment but the whole range of their other achievements, including mobility, communication and life skills.’(31) All eight QTVIs interviewed offered home visits, most within a few weeks of receiving the CVI. The type of specialist support they offer includes:

‘…help the parents in many different ways, look at how the child is responding to different to various stimulations be it light, touch, sound and helping them to work with their child to see the child’s development.’ (QTVI6)

‘What (parents) might be able to do to stimulate a child or their vision.’ (QTVI2)

QTVIs and parents expressed concerns about the possible erosion of the QTVI service – either specialist support offered by QTVIs may be replaced with generic Sensory Impairment / SS teams or the QTVI role cut entirely. QTVIs expressed real concern that CYP with VI would be severely disadvantaged if this were to happen.

“We’re a low priority… the future of (our) service isn’t secure because schools may not want to buy into it. Local authority has done an honourable thing saying these children are most at risk so we’re not going to let them be, forget them, so that’s tied into law, trying to protect those kids, there’s good will. But whether that goodwill will last? It’s all about money these days, money driving everything - cuts, cuts, cuts, cuts.” (QTVI6)

Parents also discussed the possibility that QTVI positions are at risk due to local authority cuts and worried that the specialist support they offer might disappear:

‘I want her to stay, that’s my worry…Things like braille and changing to new braille and getting the teaching assistants trained up in the local school has been all because the local VI teacher has been absolutely fantastic…(SS) don’t have the specialist knowledge do they?...We needed someone who really knew what they were talking about and she’s been fab.’ (Par4)

#### 3.5.4 Inconsistent QTVI support

Whilst most parents interviewed received significant support five of the 26 parents interviewed only received support from QTVIs after they asked repeatedly. A parent with a daughter certified as SSI recalled:

‘(*When did QTVI get involved?)* Only after a lot of pressure from us. Matter of us ringing up the education authority and insisting she had the sessions…Said they didn’t have staff.’ (Par3)

That C&R did not lead to support and parents still had to chase professionals for support frustrated them.

‘I think when she was registered I thought that everything would fall into place but even with the registration, it’s been a fight to get her access to what she needs.’ (Par15)

One parent, despite her child being certified under the age of one, waited over a year for support from education.

‘When he was about two, maybe three, saw QTVI for first time…first time I met the QTVI he was in nursery, she came to the nursery to see him.’ (Par14)

Fortunately, for most parents interviewed, support from QTVIs was more consistent.

#### 3.5.5 Certification, Registration and the statementing process

Certification and registration is a pathway to social care support. A child’s entitlement to specialist educational support comes under SEND legislation and is separate from C&R. However, registration status is evidence of a significant level of vision impairment that will be associated with high levels of need. QTVIs, the providers of specialist educational support to children with VI, were divided as to whether certification and registration helped to progress the statementing process (from September 2014 statements of special educational needs have been replaced by Education, Health and Care (EHC) Plans). One stated a CVI helped and three agreed it did ‘sometimes’.

‘The statementing process is still working here before we change over (to the Education, Health and Care plan), still rushing through a few to get kids statemented… helps schools to identify the child too, it’s more in their mind, they can put the right resources in place for that child’. (QTVI6)

Five QTVIs said C&R did not have a significant impact on the statementing process.

‘Families will ask, if they’ve got a child who might be going on for statement, would it help if they are registered. Well no, it wouldn’t because it doesn’t really matter…Our statementing people, it doesn’t make a difference in their judgement, ‘cause they judge on the evidence.’ (QTVI4)

For some QTVIs, being certified and registered was not a factor in the provision of educational support but they said it was still helpful in securing other forms of support.

‘I think sometimes parents misunderstand and think they must have registration but it’s not, it doesn’t really help in that sense at all. It is most commonly used as a lever for DLA.’ (QTVI8)

Social services in six of the seven LAs confirmed that possessing a CVI or being registered has only a minimal effect on the statementing process.

‘(It’s) more about what a child needs as an individual than driven by what CVI says…I was at a statement [meeting] yesterday and CVI was not mentioned…The report from the QTVI mentioned visual acuity…apart from that …other information didn’t come into it.’ (SS5)

‘Because the statementing or the education health and care plans are based on need I’ve never felt that certification in itself would go towards that necessarily except that it’s indirect (evidence) if a child has registration then their needs are greater and they qualify for local authority funding.’ (SS8)

Despite QTVIs claiming C&R had little effect on the statementing process, many parents reported that it did help.

‘In her statement they can’t argue certification from Great Ormand Street Hospital…Particularly for Vision Support Team and getting the right support in place - equipment, getting her work modified and adapted. You can wave the piece of paper in their face and say ‘this is it, this is what her acuities are’.’(Par15)

‘Just registered because we knew he was starting school and knew from speaking to other people he has to get this statement and I guess that was my reason for wanting him registered - was to get the statement so he could go to mainstream school and get the support he needs.’ (Par17)

Most parents said being certified and registered helped secure a statement which in turn increased the level of support they, and their child’s school, received. Parents found C&R empowering.

In order to better inform and advise parents when certification is offered ophthalmologists, orthoptists and ECLOs need to be aware of the role that parents perceive C&R plays in securing education support for their children.

#### 3.5.6 Mobility and independent living skills / Habilitation support

CYP with severe VI require assessment and training in mobility and daily living skills at various stages. This should be provided by a qualified habilitation specialist or a mobility officer trained to work with children. The ‘Local Offer’, to be implemented in September 2014, may influence provision of this type of support as each local authority is required to publish information about available local services and where parents can go locally for help. This offer should include information for CYP with VI, including habilitation and rehabilitation services.

All areas under study offered mobility and independent living skills services – most often directly from the education VI service or, less frequently, via SS. In three areas mobility officers contacted parents as soon as CVIs were received. In the other four areas QTVIs and SS stated it took some time or it was unclear when or whether this type of support was offered.

QTVIs were more informed about the level of mobility and independence service than any of the SS managers interviewed. Access to mobility education was most often at the request of parents and the QTVI most often arranged this support.

‘(Son’s) very recently just had mobility training…soon going to secondary school, so all these things more important now… (Who organised this?) QTVI. She visits him in school once every term, he has a statement in school, she advises towards that and what the school needs to do.’ (Par14)

#### 3.5.7 Support from Social Care

In contrast to the support offered by QTVIs, the support offered by SS was less substantive and consistent, but it should not be: every local authority social care department has a duty under the Children Act 1989 to safeguard and promote the welfare of ‘children in need’ in their area, including disabled children, by providing appropriate services for them. The Children and Families Act 2014 outlines new duties for social care as well as education in relation to CYP with special educational needs and disabilities. Whilst this research only examines a small sample of parents’ experiences it nonetheless reveals the **wide variation in the services offered by SS** - and in some areas QTVIs as well..

Assessments by SS were not commonly offered. Across the seven social care departments studied, assessment by SS was offered in three areas, in two areas it was ‘sometimes’ offered and in two areas it was unclear. This confirms previous research on the C&R processes in Wales that found it did not consistently lead to support: five of the 22 Welsh local authorities did not offer an assessment of needs for children following receipt of CVI and the provision of habilitation support varied widely.(32)

As discussed, 18 parents were not offered any type of support prior to certification – of these six were subsequently contacted by SS. Close to half, 12, of the 26 parents interviewed were not contacted at any point by SS.

‘SS never came, one area I’m quite annoyed with, didn’t bother taking any interest.’ (Par1)

For many parents the only contact with SS was being sent the registration card:

‘Basically I got sent a little yellow card and a letter saying please find enclosed a registration card for son. That was it.’ (Par23)

‘They just gave us the registration documents, that came through the post, and that was it. It was very hands off approach.’ (Par6)

For others the delay in being contacted by education/VI services or SS after being seen in the hospital was significant. A parent with two children certified as SSI waited a year and a half for support from education after their first child was certified and was never contacted by SS.(Par11) Another parent also waited over a year before being contacted by SS (Par4) and one parent of a child certified as SSI waited a year for services to happen after certification.

‘Once we got the QTVI on board when he was two and half she was astounded we hadn’t had anything sooner.’ (Par17)

#### 3.5.8 Good practice: Ensuring referrals & support - joint working

Across the eight local authority areas studied, four areas held joint meetings between health, education and SS. The Children and Families Act 2014 emphasises the importance of joint working to address the needs of CYP with Special Educational Needs and disabilities and requires each area to increase and improve the level of working together. The CFA 2014 expects local service providers to jointly commission services to ‘promote the well-being of children or young people who have special educational needs or a disability or where it would improve the quality of special educational provision for children and young people with special educational needs’.(33) In addition, the Royal College of Ophthalmologists guidance recommends partnership working between the parent, child and health, education and social care professionals.(25) Both sets of guidance are rooted in the ethos that communication and liaison between the different professionals and agencies involved in supporting CYP with VI is the key to delivering co-ordinated care.

In the four areas that worked jointly meetings were usually held once a term or a few times a year. In one area, the meeting included all those working with children with sensory impairments.

‘We have regular meetings with the children’s disability team, we meet once every half term, myself, teacher of deaf, team leader of deaf team, someone from adult VI service, talk about cases, transitions any of these issues that come up.’ (QTVI5)

The purpose of the meetings was to ensure children are not missed and the meetings are an opportunity for health professionals to become aware of the level of support provided by education, rehabilitation workers and SS.

‘The joint meetings we have a couple of times a year where we all meet up. Consultant knows these people and they know her and she can see the difference having social services support, the mobility training, all those sorts of things. Having access to that level of information is so important.’ (Orth1)

‘It’s a group, social care, health and education get together to try to provide a seamless service for children.’ (Orth4)

These joint meetings facilitate relationships, making it easier for professionals to pick up the phone or send an email when there is a problem - or before an issue becomes a problem.

‘I don’t think we could offer a good service if we didn’t work together as a team.’ (Orth3)

‘I really think it enhances what I can do for the families.’ (Orth1)

In addition to more formal meetings, one area held numerous informal meetings to maintain and improve communication between professionals.

‘The main thing that I think helps us is all the professionals involved meet regularly, we have a couple of different forums. One is with SS team and children with disability social worker and the education team and the other forum contains the orthoptists, ophthalmologists and the associate specialist in different hospitals. Communication is vital, knowing the person you are talking to or sending an email to really helps.’ (QTVI1)

In one area they had informal relationships and knew each other but did not meet formally to share information.

‘If I know children are under their team they get a copy of my letter, emails from them where we discuss, their queries, and teachers in my clinic a few weeks ago for a refresher.’ (Oph3)

‘We have an informal (relationship) because it’s small, it’s quite intimate and we all know each other quite well …I think it’s down to the individuals involved rather than any formal system.’ (Orth2)

Those areas without joint working practices had difficulty making contacts with other professionals.

‘I’m on my own. (when started eight years ago) it was very difficult, I tried to raise awareness of early intervention with paediatric health care centre, wanted to connect with paediatrician early …tried to instigate (joint working) here but it didn’t work, occupational therapists didn’t like it.’ (QTVI6)

Setting up a joint working network can be difficult and time consuming but two professionals (from different areas) offered advice on establishing joint working in areas where none exist.

‘You don’t have to have a family support worker (or ECLO)…but you need to have connections and the orthoptists have a good working knowledge of schools in the area. Based on network of really good communication and a very low threshold for thinking about whether or not a child would benefit from a VI service.’ (Oph4)

‘We’re lucky 'cause we’ve got orthoptists and ophthalmologists that believe that’s the way it has to be. The reality it takes time, you’ve got to start, it wasn’t perfect and people who fought against us when we started up but eventually that it becomes the culture, it becomes the norm. And therefore it kind of develops from there.’ (QTV17)

## 4. Implications of Delayed Referrals

Significant VI can delay early childhood development and learning, potentially leading to poor outcomes across a range of emotional and social wellbeing indicators that continue to affect adult life and limit work opportunities.(34) Support from birth, throughout childhood and in the transition to adulthood can reduce lifelong inequalities and improve quality of life. It is important that early assessment that results in support to improve functional vision and adaptation is offered to CYP as soon as need is indicated.

### 4.1 Support should not depend on parents’ individual efforts

When referrals are delayed and support is either absent or inconsistent, it is often left to parents’ individual actions and attitudes that result in support for their child – making support and information even more inconsistent.

‘I didn’t get a lot of support, everyone said ‘oh you’ll manage, you’re doing the right things’… You’ve got to stumble along, you have to really push quite hard to get any support.’ (Par15)

‘You’ve got to do it all yourself, nobody’s going to come and tell you.’ (Par1)

Parents understood that making support solely their responsibility could create and / or exacerbate inequalities – assertive parents received better and more support than those who were not.

‘(Pushy parents) are the ones who do well. I’m one of them.’ (Par13)

‘The parents that know how to make the noise to get it, get it.’ (Par7)

‘I know to ask because otherwise you’ll never find out. As a parent you need to know those things. You need to get them to get the support, the specialist education your child needs. People don’t know what’s available; don’t know how to fight their corner if they don’t have the information.’ (Par2)

All professionals witnessed how parents’ actions impacted on a child’s outcomes.

‘Depends on the parents and how proactive they are in wanting that information and seeking those that are on board and want to know everything and understand everything than yes, they do benefit.’ (QTVI2)

‘Parents, some are proactive, some aren’t. Proactive ones already in contact with the RNIB, disease network and know quite a lot about it.’ (SS14)

One ECLO revealed that being certified and registered can help reduce the variation in the services parents and their CYP receives.

‘Children will miss out unless their parents are very proactive and very informed. You get two ends of the see-saw - they find it very difficult, don’t understand, haven’t got the education themselves to help their child - the other end parents who do absolutely everything. There’s always going to be children who miss out and registration will play a part in that.’ (ECLO3)

This latter point is important, as a high proportion of children with vision impairment are in families experiencing social and economic disadvantage.(35)

Making parents solely responsible for securing their child’s care makes their lives even more stressful. Parents who wrongly assumed professionals would tell them what to do to best support their child and realised too late that they were expected to be assertive were devastated.

‘Do you know what? I would’ve been that (pushy) parent if someone had told me that’s what would help, that’s what I should do. I would’ve been that parent because I have always done everything for my son. I don’t care what it is, I would go to the end of earth for him. I would’ve been that parent but nobody told me how important it was. I was told treat him like a normal child and that’s what I did.’ (Par14)

## 5. Discussion

The aim of this research was to examine the C&R processes for CYP and to understand their pathways to support. The purpose of C&R for CYP is similar to that for adults - to ensure support and information. The key difference between C&R for CYP and adults is that because there is a greater range of professionals who may be involved, the processes are more complex for CYP. These professionals vary in terms of their knowledge of children and the pathways to support, which affects how they respond to the needs of CYP and their parents. The two key differences are:

Depending upon the hospital to which they are referred, CYP may be seen either by a paediatric ophthalmologist, or an ophthalmologist that works primarily with adults.

At local authority level, the key professional providing direct support for CYP is the specialist advisory teacher: the qualified teacher of children with vision impairment (QTVI). However, referral to a QTVI is not part of the C&R process.

### 5.1 Not all CYP who are eligible are being certified & 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.

### 5.2 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 procures and policies as well as the timing and nature of support for children and families.

### 5.3 Inconsistent practice for CYP with vision impairment and additional complex needs

It appears that babies with complex needs are not always referred to ophthalmology departments or offered an eye examination by an appropriate professional.

### 5.4 Difficulties in diagnosing VI in young children

Due to the difficulties in measuring visual acuity in babies and very young children, and those with additional complex needs, and the fact that some vision problems may improve as the visual system develops, ophthalmologists often wait for a firm diagnosis before they offer certification. Compared to paediatric specialists, ophthalmologists who see CYP less often certified fewer children in a year and were more likely to hesitate and delay the offer of certification. They were also less likely to understand the importance of certification for CYP.

### 5.5 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. 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.

### 5.6 The role of intermediaries such as ECLOs

Intermediaries such as specialist nurses, Eye Clinic Liaison Officers (ECLOs) and Family Support Unit workers provided practical and emotional support and information for parents in the early stages of identification of their child’s vision impairment, which was very much valued. They also provided a referral route for parents to education and other services for specialist support. However, hospitals did not always take full advantage of these intermediary roles and referring parents to them was not consistent.

### 5.7 Variable role of social care

In adults the purpose of the CVI is to provide a reliable route to support - for CYP the CVI does not appear to provide this reliable route. The support offered to children and their families by social care 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. 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 care appreciated it enormously. Support included input from a social worker (who was highly valued), respite care, and help with re-housing.

Due to cuts in Local Authority budgets there is a concern that it may become more common that the process of registering CYP is unclear and lacks an obvious pathway. As existing social care staff are asked to do more and more work, they may be unable to develop specialist knowledge as they expected to provide more general support and information. The number of CYP with sight loss is small compared to other disabilities but these smaller groups of CYP in need should not overlooked by social workers, who, admittedly are often working under increasing pressures.

### 5.8 The most valued professional was the QTVI

QTVIs were the primary source of information and support for CYP and their families. 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.

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

### 5.9 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.

### 5.10 Registers are often not held/maintained

The registration system for CYP appears to be in a poor state in many areas with many failing to update or maintain 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.

## 6. 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.

## 7. Recommendations

### 7.1 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 (36)
* 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 (37)

### 7.2 Health professionals should refer all children to local authority visual impairment teams as soon as 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 or locally developed agreements, upon identification of VI, not when diagnosis occurs.

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

### 7.4 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

Confirmation of diagnosis by ophthalmologist / orthoptist

Ophthalmologist refers to ECLO or equivalent

Where eligible, ophthalmologist initiates certification and refers to ECLO

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

### 7.5 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.

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

## Acknowledgements

Funding for this research was provided by the Royal National Institute of Blind People. Many thanks to Sue Keil for her patience and support.

Many thanks to the parents interviewed, who provided honest feedback on their family’s experiences of the C&R processes. Many thanks to the health, education and social services professionals who participated in the interviews and shared their experiences.

Finally, many thanks to the advisory group who provided useful guidance and advice throughout this project.

## Appendices

### Appendix 1 – Criteria for certification as blind or partially sighted

Generally, to be certified (and subsequently registered) as severely sight impaired (blind) a person’s sight needs to fall into one of the following categories, while wearing glasses or contact lenses that they need:

* VA of less than 3/60 with a full visual field
* VA of between 3/60 and 6/60 with a moderate reduction of field of vision, such as tunnel vision
* VA of 6/60 or above, but with a very reduced field of vision especially if a lot of sight is missing especially in the lower part of the field

To be certified (and subsequently registered) as sight impaired (partially sighted) a person’s sight has to fall into one of the following categories, while wearing glasses or contact lenses that they need:

* VA of 3/60 to 6/60 with a full field of vision
* VA of up to 6/24 with a moderate reduction of field of vision or with a central part of vision that is clouded or blurry
* VA of up to 6/18 if a large part of their field of vision, e.g. a whole half of their vision, is missing or a lot of their peripheral vision is missing.

For further information see: <http://www.rnib.org.uk/livingwithsightloss/registeringsightloss/Pages/vision_criteria.aspx>

### Appendix 2 – Interview Questions

#### Health professionals (ophthalmologists, optometrists, orthoptists)

* Job title
* Length in job (profession, not current)
* Would you describe yourself as a paediatric ophthalmologist?
* Describe CVI process
* At what stage / what factors influence when you offer certification
* For children on borderline – what is the driving a factor to offer certification?
* Different factors to consider for children with complex needs
* Department processes
* What do you tell parents about CVI?
* Type of information you provide
* What do parents ask you about CVI? / their reactions
* Do you think that certification is used as a lever to progress the statementing process?
* Do you work with SS or QTVI? How often in contact?
* What do you think are benefits of certification for children?
* What do you think is the purpose of CVI for CYP?
* Can the system be improved? How?

#### Orthoptist/ ECLO questions

* Job title/length in job
* Talk through CVI process
* Your role in the certification process / do you help fill out forms?
* What do you tell parents about CVI?
* Relationship / contact with QTVI and SS?
* What do you think is the purpose of CVI (what do you tell parents what happens after certification? Role of QTVI?)
* Can the system be improved? How?
* Do you refer patients back into clinic if they feel vision has changed and the child may be eligible for registration

#### Administrators

* Talk through CVI process
* How do you decide which social services to send to
* Relationship with ECLOs
* What do you think is the purpose of registration
* Can the system be improved? How?

#### QTVI questions

* Job title
* length in job
* Process – what is the process of referral from health to education (where from GP? Hospital)?
* How long before the service-user/parent is contacted?
* Describe the process of assessment
* Registration process - are you involved in the registration process?
* Do you ever suggest registration to the parent? Experience?
* Type of children who are not registered?
* Pupils with complex needs
* Do you continue to support YP beyond school? (Prompt mobility provision in FE)
* What do families gain from being certified and registered?
* Type relationship (frequency of contact/formalised) with:
* SS
* hospitals/health care
* Do you think that certification is used as a lever to progress the statementing process?
* What do parents ask you about registration? Main concerns?
* Why do you think parents choose not to have their children registered? (Prompt: No perceived benefits? Stigma?)
* Do you think any specific educational advantage to being registered?
* What do you think is the purpose of registration for CYP?
* Can the system be improved? How?

#### Social services

* Job title
* Process - who gets the forms in your office?
* How long before the service-user is contacted?
* How long before they are assessed?
* Describe the process of assessment
* Are they treated same as adults?
* Do you hold the register?
* How do you manage transition from CYP to adult services?
* Type of information you provide
* What do parents ask you about registration? Main concerns?
* Why do you think parents choose not to have their children registered? (Prompt: No perceived benefits? Stigma?)
* How well are parents informed of the certification and registration process before you meet them?
* Type relationship (frequency of contact/formalised) with:
* education
* hospitals/health care
* Do you think that certification is used as a lever to progress the statementing process?
* What do you think is the role of a social worker in certification/registration processes?
* What do you think is the purpose of registration for CYP?
* Can the system be improved? How?

#### Parent questions

* Gender of child
* Age of child now, Age of child when sight condition diagnosed
* Is your child registered?
* At what age was your child certified?
* Was certification at the right point / When you wanted your child to be certified? / Overall feelings on being certified
* Who mentioned it first (orthoptist, ophthalmologist, ECLO, voluntary sector (Action/RNIB), social services, QTVI, National Blind Children’s Society?)
* If through QTVI, opinion/confident this pathway works?
* What were you told about certification AND registration?
* Who told you this / written information?
* Were you able to get support for you and your child before you were offered certification and/or registration?
* Were you contacted by social services?
* If so, the length of time between referral at hospital and contact by SS?
* How has registration helped you and/or your child?
* Information in hospital
* Did anyone encourage or discourage you from certification AND/OR registering?
* Do you think the certification or registration system be improved? How?
* Ethnicity(ONS categories)
* Income (measure inequalities)
* A/B - £35 and over
* C1/C2 - £15-35k
* D/E - £5-15k

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### 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**

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3. In the Health and Social Care Information Centre data – all numbers are rounded to multiples of 5. [↑](#footnote-ref-3)