

# **RNIB NI's response to the Children's Service Co-operation Bill**

RNIB Northern Ireland welcomes the opportunity to comment on the clauses as outlined in the Children's Services Co-operation Bill. We are very pleased to have been asked to submit evidence on the Bill.

RNIB NI works to support children and adults with sight loss and enable them to live full and independent lives in an inclusive and fair society. We provide a range of services for people living with sight loss including a benefits advice service and practical support to people who have recently been diagnosed with sight loss, specialised IT support and activity programmes. In addition to our services we campaign for the promotion and improvement of the rights of blind and partially sighted people. We have 72 staff working for blind and partially sighted people across Northern Ireland and 272 volunteers engaged in supporting our work.

The estimated total of blind and partially sighted children aged 0-18 in Northern Ireland is 1708 (NI Census 2011). RNIB NI currently supports 800 blind and partially sighted children and young people and their families across Northern Ireland through Family Support, Transition & Youth Services. Our vision is that children and young people with sight loss will have the same rights and opportunities to fulfil their potential as their sighted peers (please see Appendix 1 for more detail on RNIB NI's Children and Families Services and our Youth Service).

- RNIB NI concurs that integrated working in relation to the development and implementation of children's services in Northern Ireland is paramount to ensure effectiveness in practice and better outcomes.

“When our child was diagnosed with a life-long condition which would significantly affect her vision, our world suddenly changed. So many questions needed to be answered but it was difficult to know where to turn, who to turn to and what to ask.” (Quote from parent, RNIB NI “Looking Ahead: A Parent's Guide” Booklet)

This quote is very typical of the reaction of a parent to her child's sight loss. Parents and families want to know about the services available and they want access to these services to be simple. Unfortunately, while many services exist and do great work with families, they are often not joined up. As one parent told me in the below case study (See Appendix 2)

“I feel that it is my job as a parent to keep each of these professions/services informed of what the other is doing as on the whole these services are not connected in a way in which they can freely pass information to each other on conditions as they have arisen or the progress of the child. A good example of this was in early January when the vision support teacher from the ELB couldn't understand why she wasn't included in our child's annual review in the Child Development Clinic. In her previous experience working in this field in the UK all agencies came together in a multi-disciplinary meeting to discuss a child on an annual basis.”

It is clear that it should not be the role of the parent to fill in the blanks when services are not working in a joined up way.

Conversely, we see excellent results for children and parents when these services do work together.

The RNIB NI “Looking Ahead” booklet was funded by the Children and Young People's Strategic Partnership and the Northern Outcomes Group. It includes information from Health and Social care, Education and voluntary agencies. Our feedback from parents indicates that they are grateful to have it as it helps them to navigate services.

Similarly, we see good practice in the Paediatric Low Vision Clinics in Belfast and Derry/Londonderry where statutory and voluntary agencies share expertise for the benefit of the child and family.

- We support Clause 1 of the Bill which makes it a statutory duty for Government departments to co-operate and work together effectively in devising and implementing cross cutting strategies.

RNIB NI fully supports Clause 1 and we would add that strategies and processes within each department should be standardised so that they are easily understood and followed by children and

families who are accessing their services. There is currently a different referral system in each Health and Social Care Trust and in former Education and Library Board regions. This is very confusing for organisations such as RNIB NI who make referrals on behalf of families but even more confusion for families who self-refer. We would welcome a standard process in the Health and Social Care Trusts for referring a child with sight loss. We would also like to see a standard referral process for accessing the services of Qualified Teachers of the Visually Impaired in the new Education Authority.

While it is fundamental that Government Departments work together to further achieve the six high level outcomes from its children's strategy (A ten year strategy for children and young people in Northern Ireland 2006-2016), we would also stress the importance of such departments working with voluntary organisations, such as RNIB particularly in light of the children services we deliver (see Appendix). It is important to note that RNIB NI is represented on the Disability and Transition sub-group within the Children and Young People's Strategic Partnership.

The implementation of this Bill should enhance the good co-operation seen on the CYPSP and ensure that other relevant departments become involved e.g. The Department of Employment and Learning.

- Clause 2: RNIB NI supports the need for the production and publishing of a co-operation report.

RNIB NI and other voluntary agencies should be invited to share their evaluations of partnership working and any good practice experiences at this stage.

- Clause 3: Considering the current economic climate and the severe cuts a number of Government departments are facing over the next number of years, RNIB NI support the enabling power to pool budgets and share resources. Such an approach will create opportunities for early intervention and preventative spending.

RNIB NI expresses concern at the cuts to services in both the statutory and voluntary sector which can have an adverse impact on children with sight loss and other disabilities. We stress the

need to protect existing services and focus on early intervention and support for children and families.

Research evidences the pervasive relationship between disability and poverty. (Bryne 2014; Grace, Kett, Lang and Trani 2011). While poverty as often characterised by malnutrition, poor housing, lack of access to health care and poor working condition may increase the likeliness of acquiring a disability. Disability – characterised by social exclusion, marginalisation, discrimination and/or poor educational or labour market outcomes can increase the risk of poverty.

A recent study undertaken by the Joseph Rowntree Foundation notes that the extent of the impact of Welfare Reform in NI will be wider than in GB. For example, the proportion of claimants in NI potentially affected by the under-occupation penalty and/or the change to DLA will be double the level in GB.

It is also important to note that a recent academic paper by Dr Bronagh Bryne (QUB) notes that “Children with disabilities generally are significantly more likely to grow up in poverty than their non-disabled peers.” (2014)

RNIB NI feels that it is crucial that departments collect data on sight loss and other disabilities in order to plan services. We note that there is currently no data collected on premature babies and we feel that this would be useful information to have as many premature babies can experience sight loss.

We also note that registration as sight impaired or severely sight impaired is a voluntary process and parents are not always aware of its useful nature in securing support for them and access to vital services for their child. There is often a misconception that it will adversely affect their child in later life e.g. in getting a job.

Research carried out by RNIB on certification and registration in England in 2015 found that;

1. 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.

2. There was wide variation across the hospitals and local authorities studied in the procedures for certification and registration and in the role played by various professionals. Interviews with parents – who came from across the whole of England – also found a wide variation in procedures and policies as well as the timing and nature of support for children and families.
3. It appears that children with complex needs are not always referred to ophthalmology departments for assessment by an appropriate professional. Those who have been identified as having vision impairment can often wait months or even years for the offer of certification.

While no specific research has been carried out on certification and registration on children with sight loss in Northern Ireland we know anecdotally that these findings are very similar to the experiences of families here. A clear and consistent process across all relevant departments, chiefly Health and Education is vital to ensure that we are planning for the future and children are not falling through the gaps.

- Clause 4: RNIB NI supports the need to amend the Children (Northern Ireland) Order 1995 to reflect the clauses within the Bill.
- Clause 5: RNIB NI agree that the Bill should align its definition of children and young people in accordance with the meaning as prescribed in The Commissioner for Children and Young People (Northern Ireland) Order 2003.

RNIB NI proposes that a working group is established for implementation of the Children's Co-operation Bill. RNIB NI would like to be a part of this group and we believe that the voluntary and community sector should be involved in the design phase. In the voluntary and community sector we are constantly evolving to cope with change and we are well versed in outcomes based accountability through various grants and statutory contracts. There is a wealth of skills and specific expertise that the voluntary sector could bring to the working group.

- In conclusion, RNIB NI would welcome the opportunity to present our views and potential involvement in the outworking of this legislation as well as to discuss in more detail the children services we deliver in Northern Ireland.

To conclude, RNIB NI once again thanks OFM/DFM for inviting us to give evidence today. We know the will exists to continually build on and improve existing services for children with sight loss/other disabilities and their families. We should bear in mind wider legislations such as the UN Convention on the Rights of the Child and the UN Convention on the Rights of Persons with Disabilities when we plan for better co-operation in future services. Our Children have a right to the best services that we can give them and this can only be done through multidisciplinary working. Children with sight loss and their families can face social exclusion and isolation leading to an adverse impact on their mental health and levels of confidence. If statutory and voluntary services work together to intervene at the earliest stages, we can support these children and families to avoid the economic and more importantly, the human costs of unmet potential.

# Appendices

## Appendix 1

**Children and Families Service:** supports children and young people from birth to adulthood. They receive the majority of referrals from the Eye Care Liaison Officers based in all eye clinics across Northern Ireland. They also take self referrals and referrals from other agencies such as Social Workers, Qualified Teachers of the Visually Impaired and other voluntary organisations.

When a family is referred they make contact with the parents/carers and carry out a full assessment of need. They provide advice and onward referral to both statutory and voluntary agencies. They also provide the family with a range of events from parents and tots groups, family fun days, family weekends, confidence and skills building activities for children including one to one tuition or music therapy for children with sight loss and complex needs/additional disabilities. These are regular events across Northern Ireland and are organised in partnership with a range of organisations including Angel Eyes NI, SureStart, Mencap and the National Deaf Children's Society.

In 2014 RNIB NI updated the "Looking Ahead: A Parent's Guide" booklet. The booklet is a roadmap of services for children and young people with sight loss and their families across Northern Ireland and both statutory and voluntary organisations provided their input. Topics covered include; registration, the eye clinic, statutory services and voluntary organisations.

As children reach school age they provide events focusing on education. They hold parent advice workshops with speakers from the Special Educational Needs Advice Centre (SENAC) and the Children's Law Centre. These events are held in partnership with Angel Eyes NI.

**The Realise Project:** supports children and young people aged 8-20 years old at key transition points in their lives; primary to post primary and post primary to further/higher education and employment. Through this project they provide swimming or music lessons for children as well as technology sessions, careers sessions and the IT Qualification, through workshops and on a one to one basis. The Realise Project residentials are comprised of activities designed to build skills and confidence in young people



including an option to undertake the Bronze, Silver or Gold Duke of Edinburgh Award. The Realise Project is funded by the Big Lottery Fund under their Empowering Young People Programme

Raising awareness of sight loss and eye health among children and young people is a key activity in the Children and Families Service. They provide this training in schools and youth clubs across Northern Ireland and currently reach 1500-2000 children per year.

**The RNIB Youth Service:** works with young blind and partially sighted people aged 16-25 to increase their independence, confidence and life skills through a range of programmes, activities and events. They run a series of residentials at the chalet based at the Share Holiday Village which include workshops on confidence, assertiveness and daily living skills.

Having good mobility is an important factor in assessing a person's level of employability. The role of teaching habilitation/rehabilitation for this age group is done by HSC Trust rehabilitation workers. If RNIB are supporting someone in employment or to get into employment and they require mobility training in their work environment or routes to and from work, then we refer to the appropriate rehabilitation worker in their Trust area.

## **Appendix 2**

### **Case study from a parent of a child with sight loss and complex additional needs**

I am a mother of a 28 month old child who has a number of medical conditions including severe hydrocephalus, cerebral vision impairment, astigmatism and epilepsy. Since discharge from hospital post first shunt operation our child has been in the care of our local CDC. The services there include a physiotherapist, speech therapist and occupational therapist. Our child also has a paediatrician locally as well as a neurosurgeon and a neuro paediatrician, a social worker from the sensory disability team and services from a sensory support worker in the education and library board. These are the main services provided by the health and education boards. They are all very much appreciated by us for the work they have done to help with our child's development but as you can see there are quite a large number of agencies/services for a parent to get their head round and keep on top of to get the best out of the services they provide for our child.

I feel that it is my job as a parent to keep each of these professions/services informed of what the other is doing as on the whole these services are not connected in a way in which they can freely pass information to each other on conditions as they have arisen or the progress of the child. A good example of this was in early January when sensory support teacher from the ELB couldn't understand why she wasn't included in our child's annual review in the CDC as in her previous experience working in this field in the UK all agencies came together in a multi disciplinary meeting to discuss a child on an annual basis.

In order to supplement the physio sessions the NHS could provide for our child my husband and I pay privately for weekly physiotherapy sessions. This was in no way to take from the work carried out in the local CDC but just to provide consistency in development in our child. Through the RNIB our child has also been privileged to be allowed three ten block sessions of music therapy. We have found these private services to be more open to working together for the development/progress of our child. Throughout their sessions they make regular contact to ensure that each are working together to promote the best possible outcome for our child. The sensory support teacher from the ELB even thought she has only been a designated worker for the past 7

months has recognised the potential of working with these private agencies for the greater good of our child. She also makes contact with afore mentioned to aide our child's development. I would go so far to say that without this working together of services we have sourced our child would not have made such good progress to date.

As parents we feel very strongly that a bill should be passed supporting co-operation between services. We would even go so far as to say this bill should put into legislation that in the interest of the well being of children there should be co-operation between all public services and between public and private services. This would ensure the best possible outcomes for a group of very vulnerable children.

## **Appendix 3**

### **RNIB Research 2015**

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

##### **1. Introduction**

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

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

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

## **2. Method**

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

## **3. Key findings from the research**

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

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

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

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

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

It appears that children with complex needs are not always referred to ophthalmology departments for assessment by an appropriate professional. Those who have been identified as

having vision impairment can often wait months or even years for the offer of certification.

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

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

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

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

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

The purpose of the CVI is to provide a reliable route to support but the support offered to children and their families by social services (SS) is inconsistent with some areas offering assessments and follow-up support and others not offering any support or offering

little beyond a contact letter and the registration card. In many SS departments there is a substantial lack of contact with and understanding of children with VI. Only one out of the eight LA areas studied had a fully co-ordinated approach between health, social care and education.

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

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

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

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

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

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

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

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

#### **4. Conclusions**

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

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

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

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



## **5. Further information**

The executive summary can be downloaded from:  
For further information contact [sue.keil@rnib.org.uk](mailto:sue.keil@rnib.org.uk)

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