

Children and young people Northern Ireland

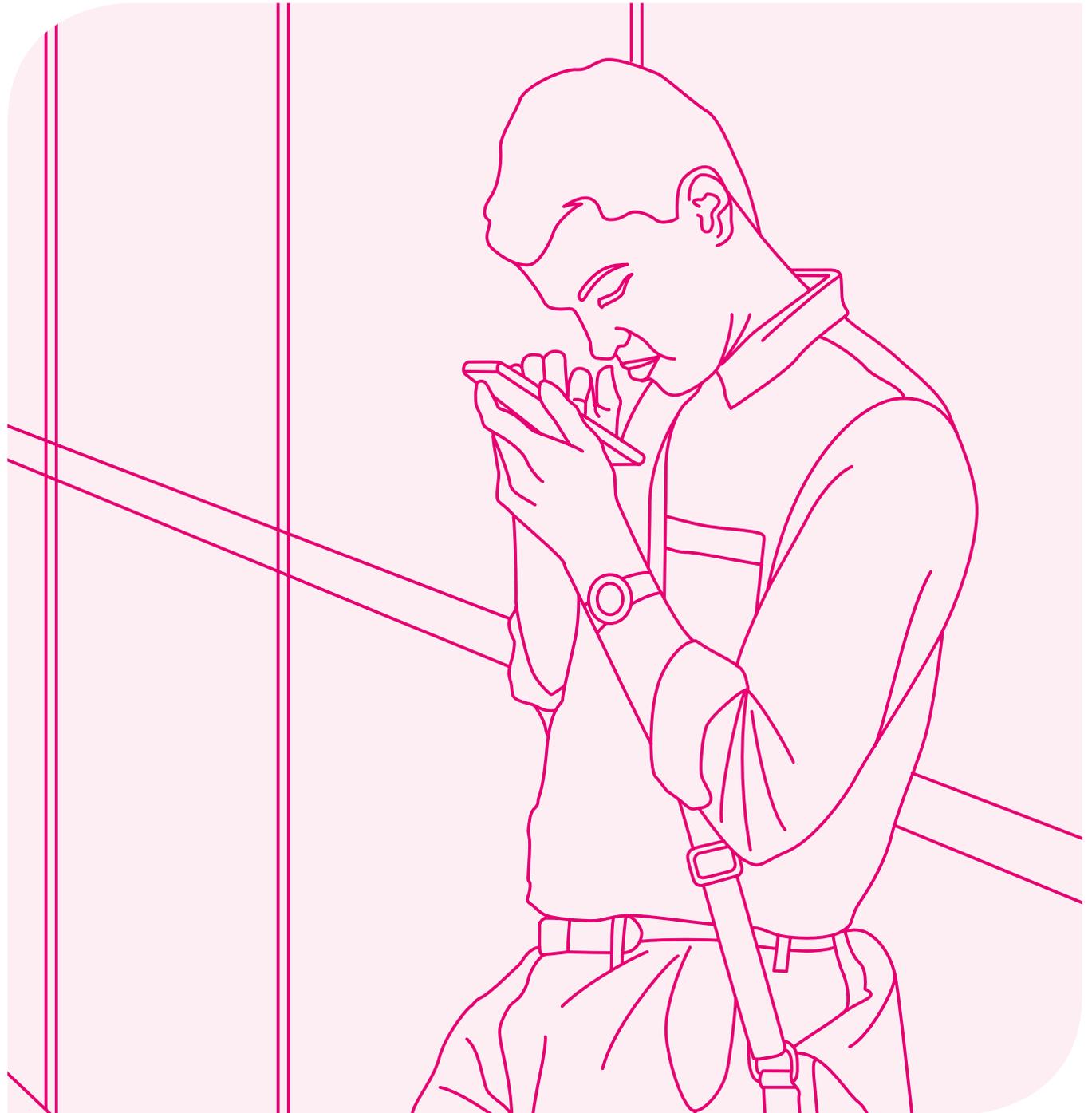
RNIB Evidence-based review

RNIB
Northern
Ireland

Supporting people
with sight loss

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Blind and partially sighted people come from every section of the community and sight loss affects people of all ages. Each is a unique individual. However there are some common issues and challenges that affect blind and partially sighted people in particular age groups.

This review looks in detail at the experience of children and young people (CYP) who are blind or partially sighted living in Northern Ireland. It includes a profile of this group, the policies that govern their access to early support, education, employment, health and social care, and a commentary on what the evidence tells us.

Where relevant it includes reference to devolved legislation but also includes a wider UK evidence base.

Profile of children and young people

Population

Vision impairment (VI) in children is a low incidence disability, but it has the potential to have an adverse impact on learning and development unless additional measures are taken to support the child/young person [1].

There are an estimated 1250 CYP aged up to 25 years with a VI in Northern Ireland. Of these approximately 900 are under 19 years old [2]. This estimate is based on visual acuity and does not include those with less severe vision impairment. Yet many children with relatively good visual acuity may have other types of difficulties with their vision that – particularly when combined with other special educational needs and disabilities (SEND) – can have implications for the child's learning and development [3; 4; 5; 6].

In fact, the 2011 NI Census reported that there were 2346 CYP aged up to 25 years with a VI in Northern Ireland. Of these, approximately 1481 were under 18 years old [7]. These figures are likely to represent a wider range of visual difficulties in children than are included in our estimates, not all affecting learning and development. In addition, the census figures are self reported and not based on clinical definitions of VI.

Of the 1025 children aged 0-19 being supported by a Qualified Teacher of learners with Vision Impairment (QTVI) in the Education Authority Regions, 298 have additional disabilities [8]. However, many children with learning difficulties (LD) in NI special education have significant visual difficulties that will impact on their education. While these were known about and recorded in their medical notes they were often absent in the statement of special educational need [9].

9,535

CYP aged under 18 were registered as blind or partially sighted with social services in England at the end of March 2014.

Causes and risks of vision impairment

Most blind and partially sighted CYP are born with their VI. Approximately two thirds of children with severe VI and blindness are diagnosed before their first birthday [10]. The single most common cause of VI in children is cerebral visual impairment. It accounts for up to 48 per cent of blindness and between 32 per cent and 45 per cent of all VI in children [11; 12]. It is likely that cerebral visual impairment is under-diagnosed, in the context of good visual acuity but impaired processing [13].

Children at most risk of severe VI or blindness are those who are born pre-term and of very low birth weight, from socio-economically disadvantaged backgrounds, or of South Asian origin [10; 3; 14; 15].

There is a high prevalence of blindness and partial sight in children with LD [16].

Research suggests that there are learners in special schools in the UK [17; 18; 19] and in NI [9] whose VI has not been identified.

CYP with VI are more likely than children without disabilities or special educational needs (SEN) to experience social and economic disadvantage [20; 21; 22].

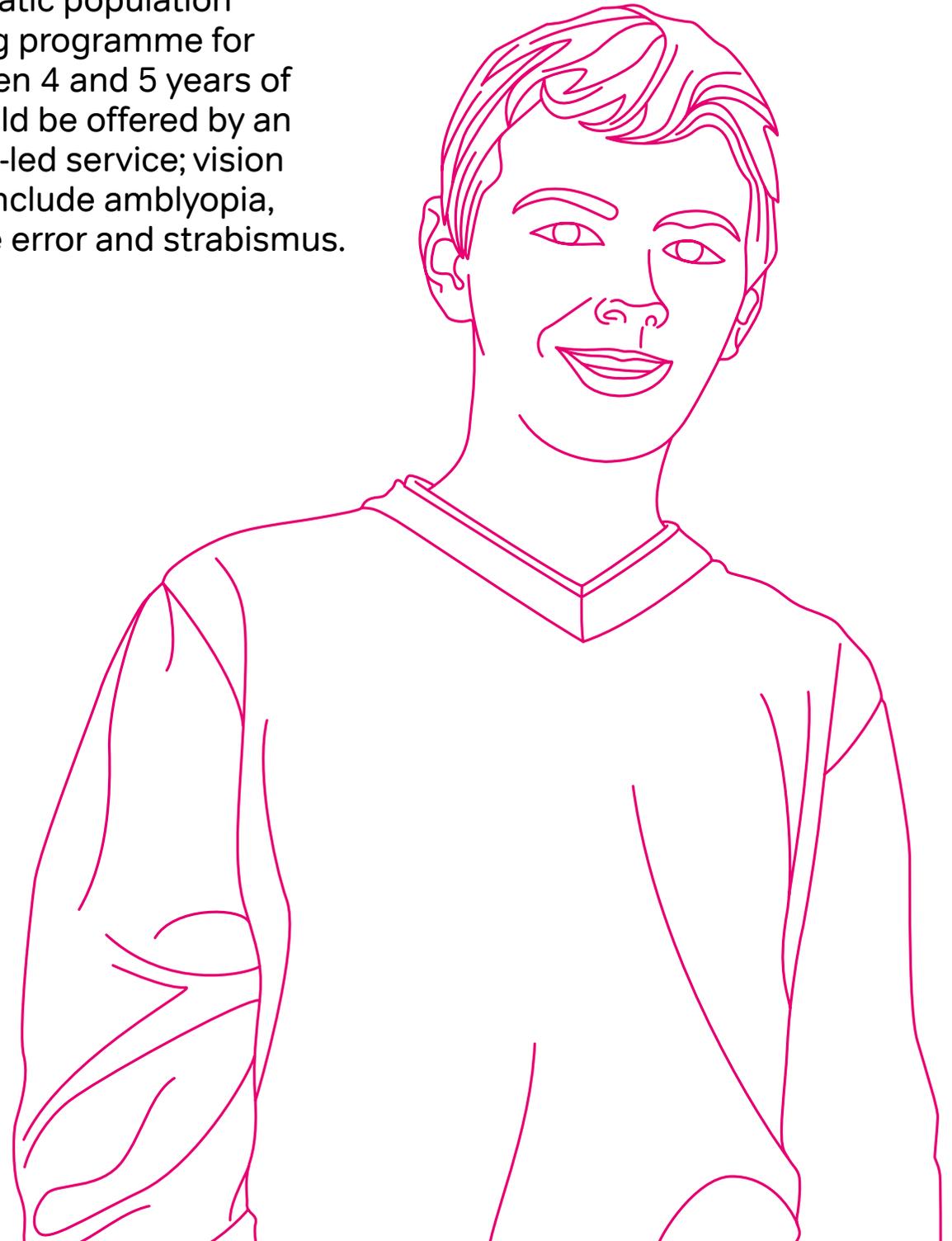
Services and support

Health screening

The UK National Screening Committee (UK NSC) is responsible for reviewing screening policies and making recommendations to ministers in each of the four UK countries about whether or not a screening programme for certain conditions should be set up. Screening procedures for vision are set out in the National Screening Committee Child Health Sub-Group Report on Vision Screening [23]:

- All newborn and 6-8 week old babies should be examined as part of the routine review to exclude retinoblastoma, glaucoma and cataract since they are treatable and, respectively, life and sight threatening.

- a systematic population screening programme for VI between 4 and 5 years of age should be offered by an orthoptic-led service; vision defects include amblyopia, refractive error and strabismus.



Education

There are currently no publically available figures for VI pupils at school in NI. However, wider evidence shows that in England the majority of CYP with VI are educated in mainstream schools [24]. In most special schools for learners with VI in England, there is now a higher proportion of pupils with additional needs than previously and the same has been found in the special school in NI compared with 30 years ago [25].

In 2013/14 there were 1040 first year students in Higher Education (HE) in the UK who were 'blind or with severe visual impairment', representing 0.14 per cent of the first year student population. Of these, 795 (76.4 per cent) were first year undergraduates and 245 (23.6 per cent) were first year post-graduates [26].

There are only 12 specialist schools for blind and partially sighted learners in the UK. Only one of these is in NI. These schools support fewer than 1000 learners, most of whom have multiple needs. There are six specialist FE colleges for learners with VI, all in England.

On 1 April 2015 the five Education and Library Boards in NI were amalgamated into one Education Authority. There was considerable variation between Education Boards in levels of educational provision for learners who have a VI. It is likely that it will take some time for the new Education Authority to agree a universal criteria for children supported by QTVI service.

The specialist practical support that CYP with VI typically require includes the following [27; 28]:

- regular input from a QTVI, both for direct teaching of specialist skills (such as learning to read and write through non-standard methods) and for advisory work
- adult support (including use of a trained teaching assistant)
- specialist equipment and access technology
- ongoing adaptation of learning resources and exams
- mobility training and independence skills, including daily living activities (habilitation)
- consistent access to low vision assessments and prescription of aids
- support for social and emotional development

- support for parent carers in the care, development and learning of their child.
- This specialist support should be available to babies and young children with VI and their families, at home, in early years settings, at school and to young people in post-school settings, via the local authority specialist education service for VI, but provision varies [24].

CYP may use non-sighted or sighted methods, or a combination of both, for reading and writing. Many use a combination of magnification, large print, electronic text and audio to access learning materials.

Of the 1025 children aged 0-19 being supported by QTVIs in the Education Authority Regions, 11 use braille [8]. Wider evidence shows that around four per cent of CYP with VI use braille as their sole or main literacy format

[29]. Some young people with multiple needs use alternative communication systems such as objects of reference.

As so many children with VI have additional needs it is important for allied health professionals and education professionals with SEN expertise to liaise with QTVIs in their support. This is important in particular where sighted methods of learning and communication comprise the main educational approach, for example CYP with autistic spectrum disorder [30].

Social care

Social care can also play an important role in the lives of families. For CYP who are eligible, and their families, registration as severely sight impaired (blind) or sight impaired (partially sighted) with one of the five Health and Social Care Trusts provides practical and financial benefits. Further information can be found at: <http://www.rnib.org.uk/eye-health/registering-your-sight-loss> Wider evidence shows that the support that parents have valued includes input from a social worker, short breaks, and help with re-housing. Parents have also found registration helpful as evidence of their child's VI when this may not always be evident, for example when the child has additional, complex needs [31].

Key professionals

Since the majority of CYP with VI are educated in mainstream settings they are taught mainly by regular teachers who are not VI specialists. Key professionals providing specialist support with this group are:

- QTVIs working for local authority VI services. QTVIs are required to hold a specialist qualification in VI in addition to qualified teacher status. Their role includes managing referrals from health to education, providing direct support to babies and young children with VI and their parents, assessing children's functional vision and liaising with health professionals, advising in mainstream and specialist settings on curriculum access, independent learning and social inclusion, guiding the work of other professionals such as teaching assistants,

teaching specialist skills (for example braille) to children and developing the visual and communication skills of those with additional or complex needs and supporting students through transition into post-16/FE education and independent adulthood.

- A mobility teacher/habilitation worker should be available to teach CYP how to move around more independently and how to do practical everyday tasks for themselves. All CYP with VI will require an initial assessment of their mobility and independence needs carried out by a qualified habilitation officer working in partnership with parents and the QTVI. National standards and training for habilitation workers with CYP were developed to make sure CYP with VI are enabled, through high quality mobility and independence training and support, to achieve the greatest

possible independence and maximise their educational outcomes and life chances [32]. These standards have not yet been adopted in NI. The All Party Working Group on VI at the NI Assembly in Stormont is currently campaigning for this to happen.

- Teaching assistants (TAs) provide in-class and curriculum support, and are employed by the schools in NI. TAs are not required to have specialist training, although courses are available, including accredited courses.
- Health specialists, such as ophthalmologists, orthoptists, and optometrists specialise in diagnosis and treatment of eye conditions, correcting vision without surgery, or measuring sight and prescribing glasses, respectively.

Policy context

It is against the law - Disability Discrimination Act 1995 (DDA) [33] - for schools and other education providers to discriminate against disabled learners of all ages. This applies to blind and partially sighted learners in early years settings, primary and secondary schools, and further/higher education. The DDA includes a duty to make reasonable adjustments, including the provision of auxiliary aids where these are not provided under the SEN route. Schools and local authorities also have an anticipatory duty: they are required to carry out accessibility planning to anticipate and improve their ability to meet the needs of disabled learners.

Since education has been devolved, the education contexts are becoming increasingly divergent in the four UK countries. Key policy documents and reviews affecting the lives of blind and partially sighted CYP in NI include the following:

2005 Special Educational Needs and Disability Order (SENDO) [34]

2006 Our ten year strategy for CYP 2006-2016 'Our CYP – Our Pledge' [35]

2009 Every School a Good School: A policy for school improvement - a review of Special Educational Needs provision [36]

2010 Healthy Child, Healthy Future — a framework for universal child health 2010: Healthy Futures 2010-2015 looks at the contribution of health visitors and school nurses in Northern Ireland [37]

2014 Delivering Social Change for Children and Young People - Office of the First Minister and Deputy First Minister [38]

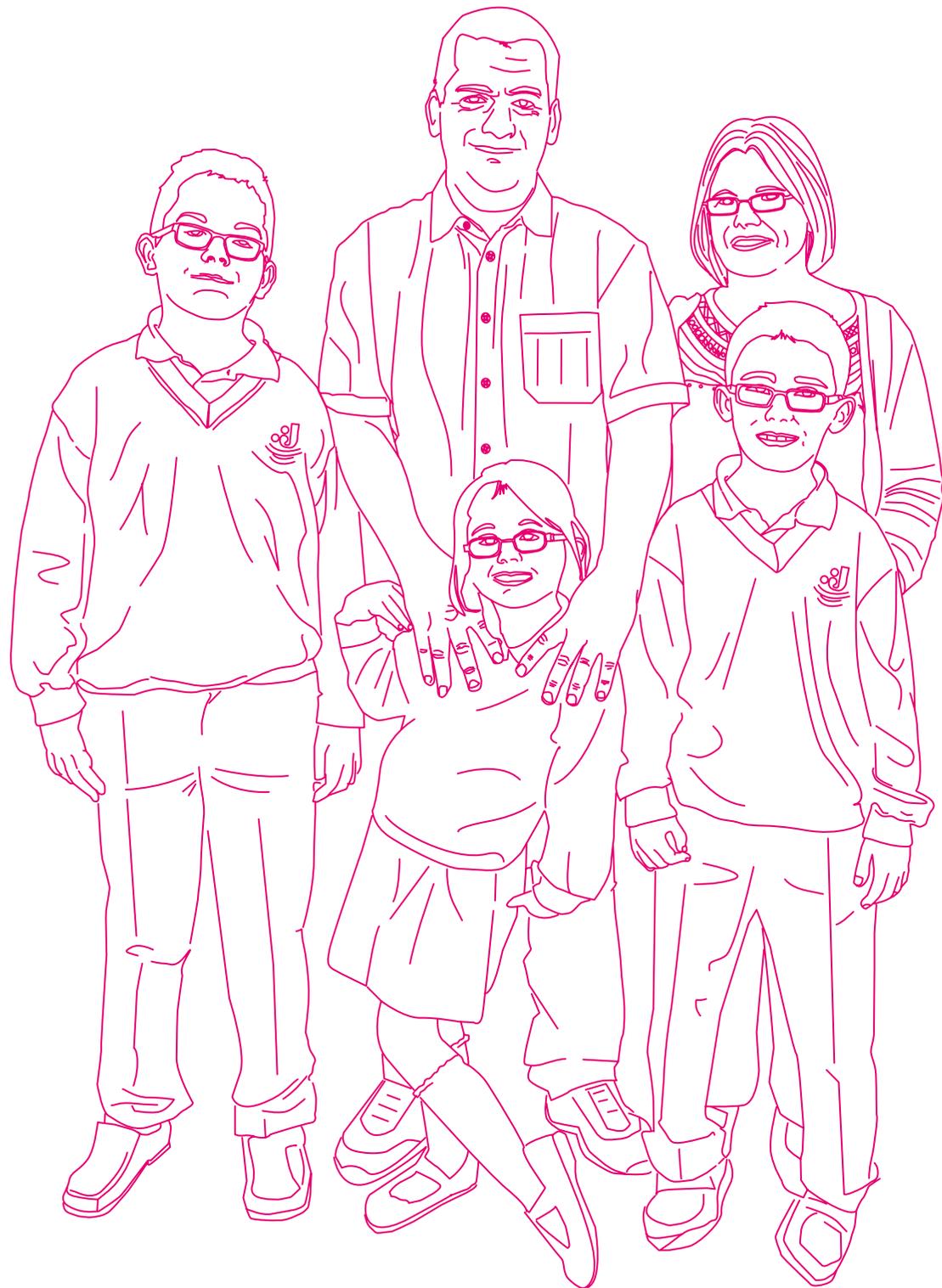
2015 Children's Services Co-operation Bill [39]

2016 SEND Bill [40]

Although some policies differ across the UK, CYP with VI face many common issues and some common themes are emerging across the four countries:

- Developing alternative statutory assessment and planning systems, building on person centred planning approaches.
- Bringing together education, health and social care provision through integrated planning and commissioning of services.
- Planning for CYP from birth through to 25 years of age to improve transitions.
- Focusing on outcomes for CYP, rather than inputs, which requires evaluation of the impact of services.
- Better experiences for CYP and their families based on greater choice and control.





Case Study

The Dickson family

Joanne and James Dickson currently live in the Newtownabbey area, County Antrim. They have three children with sight loss: Ryan 10, Kyle 8 and Emma aged 5 who attend Jordanstown School for children with sensory loss.

All three children have 'Sticklers Syndrome', a genetic, progressive condition that affects the body's collagen - the supportive tissue of the organs of the body. In the eye it affects the cornea, sclera and vitreous humour.

Ryan, the eldest child, is the most affected, being totally blind in one eye and having partial sight in the other due to a detached retina and cataracts. Over the past number of years Ryan has had several treatments for his detached

retina and cataracts and at the moment his sight is stable, but Ryan and his family live with the knowledge that an abrupt shock or blow to the head could have a disastrous affect on his already detached retina, resulting in a further loss of vision.

The family has had difficulties finding a satisfactory education environment for their children. Despite knowledge of Ryan's eye condition, Ryan's first primary school were unable to make any special arrangements such as dividing off part of the playground to reduce the risk of a blow to his head.

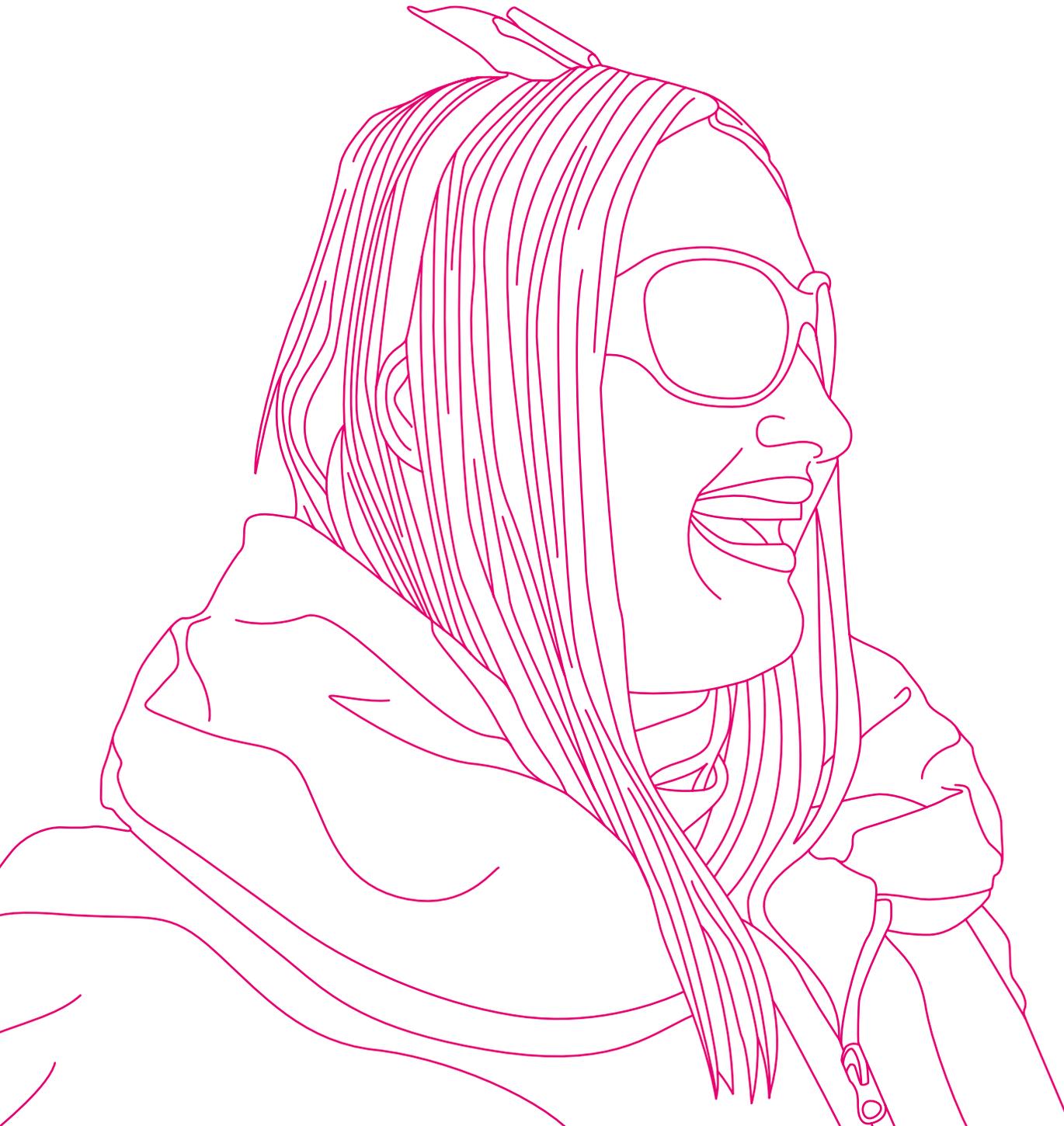
Joanne speaks about her experience of those early school days, "As parents, talking to bodies like the education board is so hard, it's intimidating. Organisations like RNIB and Jordanstown School can help speak up for us as parents of children with sight loss."

To enable Ryan to be as independent as possible now and in later life, he has had training in how to use a white cane by a Rehabilitation Officer from the Sensory Support Service based in Ballyclare.

Ryan recently attended an activity-based weekend away and took part in movie making using computer tablets. Since returning he has produced several short films, which he can now share with new friends made on his recent adventures. Although they might live all over Northern Ireland, they regularly chat using the Xbox 360 games console.



"As parents, talking to bodies like the education board is so hard, it's intimidating. Organisations like RNIB and Jordanstown School can help speak up for us as parents of children with sight loss."



“If babies with VI are not identified early and intensive health and education developmental support provided in the first two years of life, the development of the child’s social and communication skills can be seriously impeded [45]”.

Learning from the evidence base

Two sub-populations of children with VI

The population of children with VI can be thought of as two distinct sub-populations: those with and those without additional impairments/disorders [41]. The “patient journey” as well as a range of wellbeing and educational outcome measures are markedly different for children with a VI as their sole disability compared to those with VI and additional disabilities/chronic health problems [41].

Diagnosis and early support

The period around diagnosis is critical for parents to understand their child’s VI and how it might affect their child’s development and learning and the support they might need to reach their potential [42; 15; 31].

Evidence shows that VI is more likely to go undetected in children with additional disabilities, in children in some Asian ethnic groups and in children from socio-economically deprived groups [41].

Infants and young children with VI show developmental delays compared to sighted infants and are at greater risk of social communication, attention and behavioural difficulties [43; 44]. If babies with VI are not identified early and intensive health and education developmental support provided in the first two years of life, the development of the child’s social and communication skills can be seriously impeded [45]. Blind children, in particular, require high levels of specialist input to address crucial needs in their cognitive development, communication, social and independence skills [46].



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Emotional wellbeing and social relationships

Wider research shows that at age seven, children with VI in the Millennium Cohort Study (MCS) differ across a range of characteristics associated with wellbeing when compared with sighted seven-year-olds. For example their parents were significantly more likely to say that their child had emotional, concentration or behaviour difficulties; was often unhappy, downhearted or low; and wet the bed at least once a week [20]. At age eleven, their parents were significantly more likely to say that the child was nervous or clingy in new situations, and to often seem worried. While eleven-year old children with VI were just as likely as other children to feel they were a person of value, to feel good about themselves, to consider they had a number of good qualities, and to feel happy with the way they look, they were less

likely than other children to feel that they were able to do things as well as others [22].

Other research has found lower quality of life scores in children with VI [47].

Parents and teachers of seven and eleven-year-old children with VI were significantly more likely to say that the children were being bullied, than parents and teachers of children without VI [20; 22].

At ages seven and eleven, children with VI plus an additional SEND are at particularly high risk of poor outcomes across a range of emotional and social wellbeing indicators [20; 22]. For example, at the age of eleven children with sight impairment and additional SEND were less likely than other children to be happy and more likely to feel worried [22].

CYP with VI are regular users of information technology including mobile phones, and communicate regularly through social networking sites such as Facebook [48; 22]. However, this is less likely to be the case for children with VI and additional SEND [22]. CYP with VI are also interested in a wide range of leisure activities [49; 22]. At the age of eleven however, there is some evidence to suggest that they are less physically active than other children [22].

 “Children of school age with VI have been found to have poorer use of language for social communication than their fully sighted peers [50]”.

Children aged seven with VI in the MCS were just as likely as fully sighted children to say they had “lots” of good friends [20], while those who took part in the survey at the age of eleven were just as likely as other children to be happy with their friends and according to their parents and teachers to have at least one good friend [22]. This is supported by another study of young people with VI in school and further education settings which found most had a good network of friends [48]. However just under half of the 50 participants in an Action for Blind People survey of 14 to 25 year olds with VI (around half of whom were currently accessing Action for Blind People services) cited a lack of social life/friends as one of the three issues that affected them [49]. Children of school age with VI have been found to have poorer use of language for social communication than their fully sighted peers [50].

At the ages of seven and eleven, children in the MCS who had VI **and** additional SEND differed from other children of the same age on a number of variables related to friendships and social activities, indicating that this group may be at higher risk of social exclusion than children with sight impairment as their only SEND. It is important to note that severity of VI was not taken into account [20; 22].

Curriculum access and attainment

At all key stages the attainment of learners with VI (as a SEND group) is lower than that of learners with no SEND, but higher than any other SEND group. We also know that at all ages, learners with VI as their only SEND do better in terms of their attainment and progress than learners with a VI plus an additional SEND [21; 51; 22]. The current evidence on educational attainment does not tell us the effect (if any) of severity of VI.

Analysis of the MCS has found differences at the ages of seven and eleven between children with and without VI on several school related variables. For example, at the age of eleven children with sight impairment were more likely than other children to feel tired at school and were less likely than other children to feel that they could do things as well as most other people. However,

the majority of children with VI (with and without additional SEND) were happy with and liked their school and liked the core curriculum subjects and considered they were good at them [22].

Although most CYP with VI are educated in mainstream settings, as VI is a low incidence disability, mainstream teachers rarely encounter learners with VI. They often struggle to teach CYP with VI effectively, having had little opportunity to develop alternative strategies. Evidence reveals poor planning by teachers [52] and concerns that an emphasis on provision of accessible materials is leading to a reduced focus on supporting independent learning through the use of low vision aids and assistive technology [53]. Mainstream technology with built in accessibility options is being used increasingly by young people with VI, but needs to be

part of a range of strategies for accessing information [54; 55].

Key longer term independence skills (including mobility and social skills) that fall beyond the academic curriculum may be neglected [56; 55; 57; 58].

Although Teaching Assistants (TAs) play an important role, evidence relating to pupils with SEN (but not VI) shows that they may also prevent social inclusion and have an adverse effect on educational attainment by acting as a barrier between the child, their peers, and their teacher [59]. Evidence indicates that TAs can best support children with VI if they have an understanding of VI and how it affects the individual [56]. Wider evidence shows that there are over 2400 TAs supporting CYP with VI in England. The majority were employed directly by individual mainstream schools but this is

an under-representation as not all local authorities were able to provide numbers of TAs in mainstream schools. This is a matter of concern as it indicates that there may be TAs working without the supervision of a QTVI from the local authority VI service [60; 29].

A recent study recommended the development of national standards, resources and teacher training for specialist teachers to enable them to teach literacy through braille since many QTVIs feel ill equipped to do so [61]. In response, RNIB has recently developed an online training course to support QTVIs in how to teach literacy through braille.

Subject specific expertise has declined with the closure of many specialist VI schools. This can lead to difficulties when learners are entered for national tests and exams because

classroom practice may not always correspond with exam provision [62].

Curriculum access issues are exacerbated by public sector cuts leading to reduced staffing in local authority VI services and thresholds for access to support being raised as a consequence [60].

Transition to further study, training and employment

While most young people with VI describe their experience of transition from school as fairly positive, they have identified the need for better planning, preparation and information, including the opportunity to meet their new education provider in advance [63].

There is evidence of ‘churning’ for some young people with VI, meaning that their progress through post-school education is delayed because they repeat

a year of an education course, or repeatedly take courses at the same level (or even lower levels) [54; 64].

Research has also found that many young people with VI have poor mobility and independence skills, and that this becomes more of a problem as they move into further and higher education [55; 57].

Students with VI who had successfully completed college courses emphasised that computer, assistive technology and keyboard skills were important and necessary skills to have before going to college [65]. Successful transition to university includes: applying for disabled student allowance (DSA) at the earliest opportunity; researching in advance for DSA assessments assisted by those with specialist knowledge; negotiating support agreements in good time; good self advocacy skills; good mobility

and ICT skills with appropriate training prior to the start of the course [66].

For further evidence about the transition experiences of CYP, a longitudinal study is being carried out by the University of Birmingham and RNIB. Visit <http://www.rnib.org.uk/knowledge-and-research-hub-research-reports/education-research-for-more-information>.

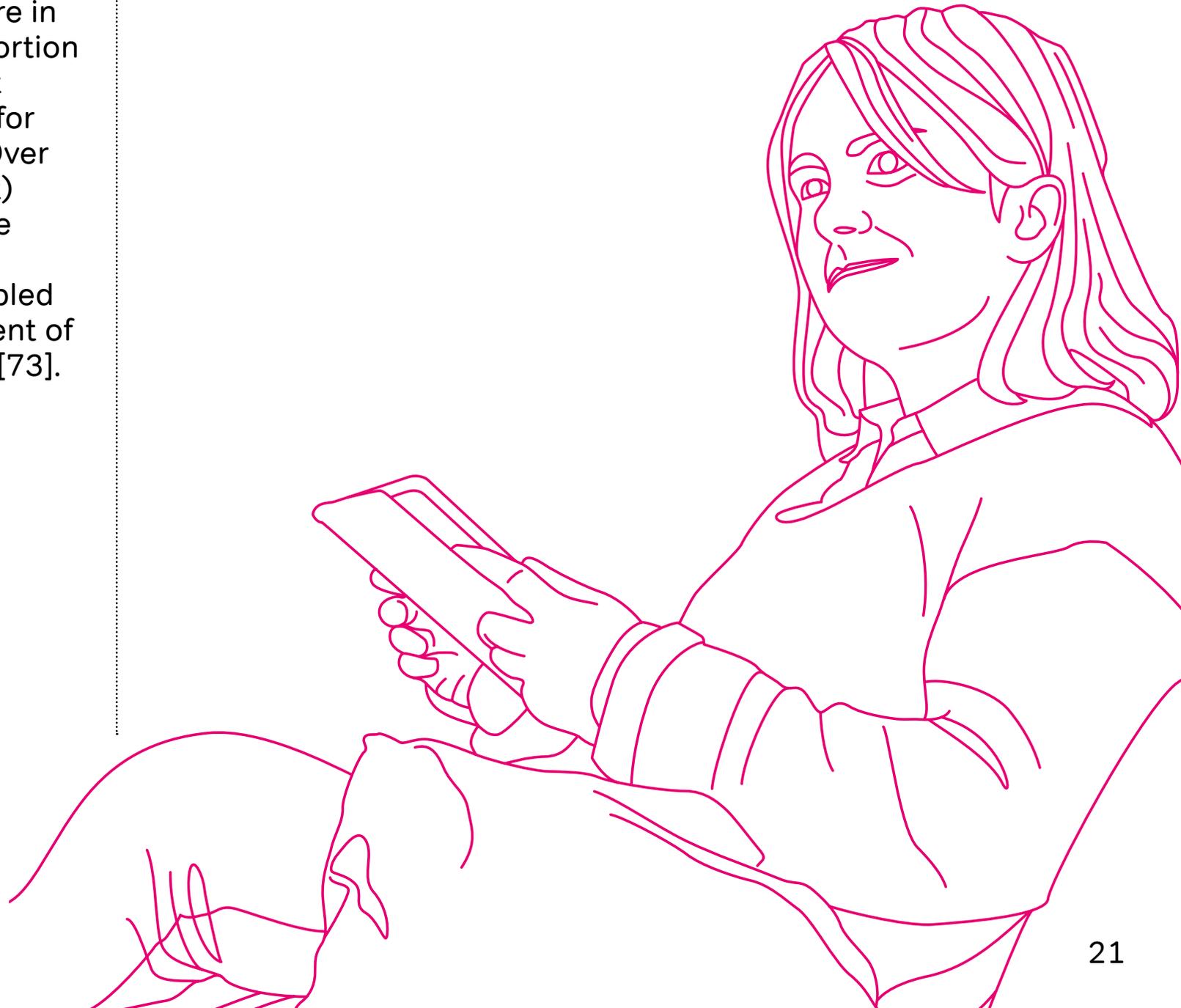
Factors that contribute to successful transition of young people with complex needs from residential school provision include:

- personalised support from the age of 14
- better and earlier provision of information for parent carers and the provision of a written transition plan to families

- involvement of senior management to ensure integrated working between adult and children's services and across sectors and local authorities
- dedicated transitions workers supporting the young person and their parents through the process of transition [67; 68].
- Analysis of the Labour Force Survey shows that fewer 16 to 25 year olds 'disabled due to a seeing difficulty' were employed compared to all young people in this age group. They were also twice as likely to be NEET (not in education, employment or training) [69].
- For blind and partially sighted people, holding an educational qualification is a key enabler for obtaining employment [56]. In addition to employers' attitudes, factors that determine a blind or partially sighted person's distance from the labour

market, and whether they are ready for work, are detailed in the Evidence-based review of people of working age [70]. They include independent mobility skills, assistive technology skills and skills to communicate needs and associated adjustments to employers. Research carried out in the USA showed that factors associated with employment of young people with VI aged 19-23 included multiple work experiences, completing a post-secondary programme of study, independent travel skills and peer social skills [71]. Yet evidence suggests that young people with VI are less likely than their peers to have experience of paid employment, and that independent travel may be an aspiration rather than a reality for some, particularly those with more severe VI [49; 72].

- In 2013, 38.9 per cent of graduates with VI found full time employment and a further 15.8 per cent were in part time jobs. The proportion in part time employment was slightly higher than for all disabled graduates. Over one in ten (11.4 per cent) of graduates with VI were unemployed, compared with 8.0 per cent of disabled graduates and 5.4 per cent of non-disabled graduates [73].



What the evidence tells us

Policy makers should plan for two sub-populations of children with VI

- Experiences of health, education and social care are different for children with a VI as their sole disability compared to those with additional disabilities. Policy makers, commissioners and service providers should take into account the different needs of these groups: when analysing and interpreting statistics and developing wellbeing and educational outcome measures, the population of children with VI should be divided into those with and those without additional disabilities.

Early diagnosis and support is crucial

- Unlike adults, most children with VI have conditions that are present from birth or diagnosed in the first year of life. Professionals supporting babies and young children and their families should have specialist training in childhood VI and should be encouraged to use the Developmental Journal for Babies and Children with Visual Impairment [74].
- The majority of these children need specialist support to minimise the developmental (and sometimes the emotional and psychological) impact of VI. At the point of diagnosis of a VI, the whole family needs to be scaffolded in a way that promotes a positive, aspirational approach to addressing potential challenges as the child grows up. Parents are looking for emotional and practical

guidance on methods of care, nurture, play techniques, resources and welfare advice. Therefore, babies and children with VI should be referred as soon as possible after identification to the local authority specialist VI education advisory service for support from a QTVI. Vision 2020 UK has a recommended pathway for CYP with VI [75]. See also Boyce, 2015 [31].

- At least 50 per cent of CYP with VI have additional disabilities and/or chronic health problems, including many with multiple and complex needs. RNIB believes that all children with special needs should have a full vision assessment carried out by an ophthalmic team on school entry, as well as regular orthoptic and optometric assessment in special schools throughout their school life with a clear plan for transition to adult services.

- The National Screening Committee recommends that all children in mainstream schools are vision screened in reception aged 4-5 years but children attending special schools require much more in-depth and specialist assessment of their functioning vision.
- Wider evidence shows that parents of children who are registered say that registration is important to them, yet there is evidence that not all local authorities (In England, where this study was carried out, local authorities carry out the functions of the Education Authority and Health and Social Care Trusts) are maintaining their register for children. The offer of registration should include the offer of a social care assessment. Parents who receive support from social care value it highly. However, the support offered to children and their families by social

services is inconsistent with some areas offering little or no support at all [31].

Emotional wellbeing and social relationships are risk areas

- Children with VI are at risk of poor outcomes across a range of emotional and social wellbeing indicators and the risks are even greater for children with VI and another disability.
 - It is important that the additional curriculum, which includes independence, daily living and social skills (known as habilitation skills) is given equal priority with academic attainment, in order that CYP are fully included with their peers, and adequately prepared for the transition to independent adulthood.
- All CYP with VI are entitled to a full assessment by a registered qualified habilitation specialist, with education and habilitation provision in accordance with their assessed need.
 - Parent carers, mainstream education and specialist support all have a role to play in providing social skills and independence training to CYP with VI.



Young people with additional needs making the transition from residential settings should also have the support of a dedicated transition worker.



Specialist support is essential for curriculum access and attainment

- Awareness raising among mainstream teachers of the effects of VI on learning is key to inclusive provision. All those supporting learners with VI should have specialist training to ensure that they enable rather than prevent inclusion and independent learning. All CYP with VI should be entitled to a full assessment by a QTVI.
- CYP with VI form a diverse but low incidence group. As a result, the way to support professionals is to identify evidence of effective practice models and address the challenge of how best these can be implemented in practice, given that most CYP are educated in non-specialist VI settings.

Early preparation is needed for transition to further study, training and employment

- Evidence shows that if young people with VI, with and without additional disabilities, are to be equipped with the skills required to succeed in post-school settings greater emphasis is required, during schooling, on developing their independent learning and social skills. Information and guidance should be provided to young people while at school, and to their parents, about the options available, including Access to Work – the government support programme that aims to help more disabled people start or stay in work. Young people with additional needs making the transition from residential settings should also have the support of a dedicated transition worker.

- Tracking destinations and providing support systems are needed to prevent young people becoming socially isolated and NEET (not in education, employment or training) when they leave education.

References

1. National Sensory Impairment Partnership

www.natsip.org.uk

2. ONS (2013) National Population Projections for 2015, 2012-based projections release. Office for National Statistics.

3. Cumberland, Pathai and Rahi (2010) 'Prevalence of eye disease in early childhood and associated factors: findings from the millennium cohort study'. *Ophthalmology* 2010, 117: 2184-2190

4. Rogers (1996) 'Vision impairment in Liverpool: prevalence and morbidity' *Archives of Disease in Childhood*, 74: 299 – 303

5. Flanagan, Jackson, Hill (2003). Visual impairment in childhood: insights from a community-based survey. *Child Care Health Dev.* 2003 Nov;29(6):493-9.

6. Bone and Meltzer (1989) OPCS surveys of disability in Great Britain Report 3: The prevalence of disability among children London: HMSO

7. Northern Ireland Statistics and Research Agency. Census 2011 <http://www.nisra.gov.uk/census/2011Census.html>

8. RNIB (NI) (2015) Freedom of Information (FOI) request to Education Authority in Northern Ireland

9. Little and Saunders (2015) A lack of vision: evidence for poor communication of visual problems and support needs in education statements/plans for children with SEN. *Journal of the Royal Institute of Public Health*, Feb;129(2):143-8

10. Rahi and Cable (2003) 'Severe visual impairment and blindness in children in the UK' *The Lancet*, Vol 362, Oct 25, 2003

11. Mitry, Bunce, Wormald, and Bowman (2013) 'Childhood VI in England: a rising trend'. *Archives of Disease in Childhood* 2013; 98: 378-380.

12. Mitry, Bunce, Wormald, Leamon, Simkiss, Cumberland, Rahi and Bowman (2013) Causes of certifications for severe sight impairment (blind) and sight impairment (partial sight) in children in England and Wales. *British Journal of Ophthalmology* 2013; 97: 1431-1436.

13. Macintyre-Béon, Young, Dutton, Mitchell, Simpson, Loffler, Bowman, Hamilton. Cerebral visual dysfunction in prematurely born children attending mainstream school.

Doc Ophthalmol. 2013 Oct;127(2):89-102. doi: 10.1007/s10633-013-9405-y. Epub 2013 Aug 31.

14. Hamblion, Moore and Rahi (2012) 'Incidence and patterns of detection and management of childhood-onset hereditary retinal disorders in the UK. *British Journal of Ophthalmology* 2012, 96: 360-365

15. Solebo and Rahi (2014) *Epidemiology, aetiology and management of visual impairment in children. Arch Dis Child* 2014, 99: 375-379

16. Das, Spowart, et al. (2010). 'Evidence that children with special needs all require visual assessment.' *Archives of Disease in Childhood* 95(11): 888-892.

17. Woodhouse, Ryan, Davies and McAviney (2012) A clear vision: eye care for CYP in special schools in Wales. School of Optometry and Vision Sciences, Cardiff University and RNIB Cymru. Project funded by the Welsh Government through the Children's Low Vision Project.

18. Woodhouse, Davies, McAviney, Ryan (2014) Ocular and visual status among children in special schools in Wales: the burden of unrecognised visual impairment. *Arch Dis Child.* 2014 Jun;99(6):500-4.

19. Bunce (2012) Visual Impairment in special schools in the UK. Unpublished report for RNIB.

20. Harris, Keil, Lord and McManus (2012) Sight impaired at age seven: Secondary analysis of the Millenium Cohort Study. RLSB, RNIB and NatCen Social Research

21. Chanfreau and Cebulla (2009) Educational attainment of blind and partially sighted pupils. National Centre for Social Research (NatCen) for RNIB.

22. Harris, Keil, Lord and Lloyd (2014) Sight impairment at age eleven: Secondary analysis of the Millennium Cohort Survey. RLSB, RNIB and NatCen Social Research

23. Hall and Elliman (2006) Health for all Children. OUP Oxford; New ed of 4 Revised ed edition.

24. Keil (2012) RNIB survey of VI services in England and Wales 2012: Report for England. RNIB

25. McClelland, Julie, Saunders, Kathryn, Hill, Nan, Magee, Anne, Shannon, Myrtle and Jackson, Jonathan (2007) The changing visual profile of children attending a regional specialist school for the visually impaired in Northern Ireland. Ophthalmic & Physiological Optics 27(6):556-60.

26. Higher Education Statistics Agency (2015)
<https://www.hesa.ac.uk/content/view/1973/239/>

27. DfES (2002) Quality Standards in Education Support Services for CYP with Visual Impairment
http://webarchive.nationalarchives.gov.uk/20081230134948/http://www.teachernet.gov.uk/_doc/6576/quality%20standards%20-%20visual%20impair.htm

28. The Education and Training Inspectorate, 2012 Report of an Evaluation of Provision for Pupils with a Visual Impairment in mainstream Schools in Northern Ireland. The Education and Training Inspectorate

29. Keil (2016) Report on findings from RNIB Freedom of Information (FOI) requests 2015. RNIB. Awaiting publication.

30. Pring (2004) (Ed) Autism and blindness: Research and reflections .Wiley.

31. Boyce (2015) Ensuring Support: Certification and Registration in CYP with VI in England. Report commissioned by RNIB

32. Department for Children, Schools and Families (2011) Quality Standards: Delivery of Habilitation Training (Mobility and Independent Living Skills) for CYP with Visual Impairment
http://www.rnib.org.uk/sites/default/files/qs_for_the_delivery_of_habilitation_training.pdf

33. Disability Discrimination Act 1995 <http://www.legislation.gov.uk/ukpga/1995/50/contents>

34. Special Educational Needs and Disability Order (SENDO) <http://www.education-support.org.uk/parents/special-education/sendo/>

35. Our ten year strategy for CYP 2006-2016 'Our CYP – Our Pledge' <https://www.executiveoffice-ni.gov.uk/publications/ten-year-strategy-children-and-young-people-northern-ireland-2006-2016>

36. Every School a Good School: A policy for school improvement - a review of Special Educational Needs provision. <http://www.belb.org.uk/Documents/613.pdf>

37. Healthy Child, Healthy Future — a framework for universal child health 2010 <https://www.health-ni.gov.uk/publications/healthy-child-healthy-future>

38. Delivering Social Change for children and young people - Office of the First Minister and Deputy First Minister <https://www.executiveoffice-ni.gov.uk/articles/delivering-social-change-introduction>

39. Children's Services Co-operation Bill <http://www.niassembly.gov.uk/assembly-business/legislation/current-non-executive-bill-proposals/childrens-services-co-operation-bill/>

40. Special Educational Needs and Disability Bill <http://www.niassembly.gov.uk/assembly-business/legislation/primary-legislation-current-bills/special-educational-needs-and-disability-bill/>

41. Rahi, Cumberland, Peckham (2010) 'Improving Detection of Blindness in Childhood: The British Childhood VI Study' *Pediatrics* 2010;126:e895-e903

42. Cole-Hamilton (1996) *Taking the Time: telling parents their child is blind or partially sighted*. London: RNIB

43. O'Reilly, Sakkalou, Sakki, Dale N, Salt, Dale N J (2014) *Behaviour difficulties in the early years of children with profound or severe visual impairment*. The Royal College of Ophthalmology Congress, Birmingham, May 2014.

44. Sakkalou, O'Reilly, Sakki, de Haan, Salt, Dale (2013) Early brain and social development in infants with severe visual impairment at risk of autism. Annual Scientific Meeting of the British Autism Study of Infant Siblings, Birkbeck College, London, October 2013.

45. Dale and Sonksen (2002) 'Developmental outcome, including setback, in young children with severe visual impairment' *Developmental Medicine and Child Neurology* 2002, 44: 613-622

46. Perez-Pereira and Comti-Ramsden (1999) *Language Development and Social Interaction in Blind Children* Psychology Press, Sussex

47. Chadha and Subramanian (2010) 'The effect of visual impairment on quality of life of children aged 3-16 years'. *British Journal of Ophthalmology*, 2010

48. Hewett, Douglas, Ramli and Keil (2012) Post-14 transitions – A survey of the social activity and social networking of blind and partially sighted young people: Technical Report. VICTAR, university of Birmingham and RNIB

49. Wright, Vince and Keil (2011) Survey regarding services for blind and partially sighted young adults. Action for Blind People.

50. Tadic, Pring and Dale (2010) 'Are language and social communication intact in children with congenital visual impairment at school age?' *Journal of Child Psychiatry*, 2010, June, 51(6) 696-705

51. Bassett (2010) Educational progress of young blind and partially sighted pupils. Statsconsultancy for RNIB.

52. Keil, Parris, Cobb, Edwards and McAllister (2006). Too little, too late: Provision of textbooks to blind and partially sighted children. RNIB.

53. Khadka (2010) Development of the Cardiff Visual Ability Questionnaire for CYP (unpublished PhD dissertation), School of Optometry and Vision Science, University of Cardiff.

54. Hewett, Douglas, Keil and Williams (2015) The Transition Experiences of Young People with VIs aged 17-21. Technical report of findings to February 2015. VICTAR, University of Birmingham funded by the Nuffield Foundation.

55. Hewett (2015) Learning to be independent in school and college. Presentation at RNIB and University of Birmingham national transitions conference, 1 July 2015 <http://www.rnib.org.uk/transitionconference>

56. Douglas, McCall, McLinden, Pavey, Ware and Farrell (2009) International review of the literature of evidence of best practice models and outcomes in the education of blind and visually impaired children. VICTAR, University of Birmingham and St Patrick's College, Dublin report for NCSE. NCSE Research Report no. 3

57. Hogg (2015) Being independently mobile. Habilitation provision research results. Blind Children UK/ Guide Dogs Family presentation at RNIB and University of Birmingham national transitions conference 1 July 2015 <http://www.rnib.org.uk/transitionconference>

58. Sapp and Hatlen (2010) 'The Expanded Core Curriculum: Where we have been, where we are going, and how we can get There' **Journal of Visual Impairment and Blindness**, June 2010, 338-348

59. Blatchford, Russell and Webster (2012) Reassessing the impact of teaching assistants: How research challenges practice and policy. Routledge: London.

60. Keil (2015) Local authority VI (VI) education service provision for blind and partially sighted CYP: Report on findings from RNIB Freedom of Information (FOI) requests 2014. RNIB

61. McCall, McLinden and Douglas (2011) A review of the literature into effective practice in teaching literacy through braille. VICTAR, University of Birmingham report for RNIB.

62. Cobb (2008) Exploring systems for the provision of modified print examination papers to partially sighted candidates in England and Wales. Unpublished MPhil thesis, School of Education, University of Birmingham

63. Hewett, Douglas and Williams (2011) Post-14 transitions support – a survey of the transition experience of visually impaired young people. Technical report of findings to summer 2011. VICTAR, university of Birmingham report for RNIB

64. Hewett (2015) Pathways through transition: Participants who are NEET (Not in Employment, Education or Training) or in a vulnerable **position** Presentation at RNIB and University of Birmingham national transitions conference, 1 July 2015 <http://www.rnib.org.uk/transitionconference>

65. Trief and Feeney (2003) 'Guidelines for a pre-college curriculum for students with blindness and visual impairments' RE:view, 35(3), 137

66. Hewett and Douglas (2015) Pathways through transition: Participants who transitioned into Higher Education. Presentation at RNIB and University of Birmingham national transitions conference, 1 July 2015

<http://www.rnib.org.uk/transitionconference>

67. Beresford and Cavet (2009) Transitions to adult services by disabled young people leaving out of authority residential schools. Social Policy Research Unit, University of York, York.

68. Keil (2011) Internal RNIB evaluation of transition of young people from RNIB Pears centre for specialist learning: A Brief Review of the Literature. RNIB: Birmingham

69. Hewett with Keil (2015) Investigation of data relating to blind and partially sighted people in the Quarterly Labour Force Survey: October 2011 – September 2014. VICTAR, University of Birmingham report for RNIB.

70. RNIB (2016) Evidence-based review: People of working age. RNIB

71. Capella McDonnal (2011) 'Predictors of employment for youths with visual impairments: Findings from the second national longitudinal transitions study'. Journal of Visual Impairment and Blindness, August 2011, 453-466.

72. Douglas (2015) Finding Work. Presentation at RNIB and University of Birmingham national transitions conference, 1 July 2015 <http://www.rnib.org.uk/transitionconference>

73. AGCAS (2015) What happens next? A report on the first destinations of 2013 disabled graduates. AGCAS Disability Task Group. June 2015.

74. Developmental Journal for Babies and Children with Visual Impairment
<http://www.councilfordisabledchildren.org.uk/what-we-do/our-networks/early-support/early-support-resources>

75. Vision 2020 UK (2014) Guidelines and Pathway for putting the UK Vision Strategy into Action for CYP (0 to 25 years) with VI, and their Families **<http://www.vision2020uk.org.uk/guidelines-and-pathway-for-putting-the-uk-vision-strategy-into-action-for-children-and-young-people-0-to-25-years-with-vision-impairment-and-their-families-2/>**

About our evidence

RNIB is a leading source of information on sight loss and the issues affecting blind and partially sighted people.

Sight loss data tool

Our Sight loss data tool provides local and regional facts and figures about blind and partially sighted people and those at risk of sight loss.

[rnib.org.uk/datatool](https://www.rnib.org.uk/datatool)

Research reports

We carry out and commission a wide range of research on the issues that affect blind and partially sighted people.

[rnib.org.uk/research](https://www.rnib.org.uk/research)

Knowledge Exchange Network

The Knowledge Exchange Network for the Sight Loss Sector has been set up to help professionals generating and using research and information on sight loss. To find out what the network can offer, and to receive our email updates visit:

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