

Children and young people England

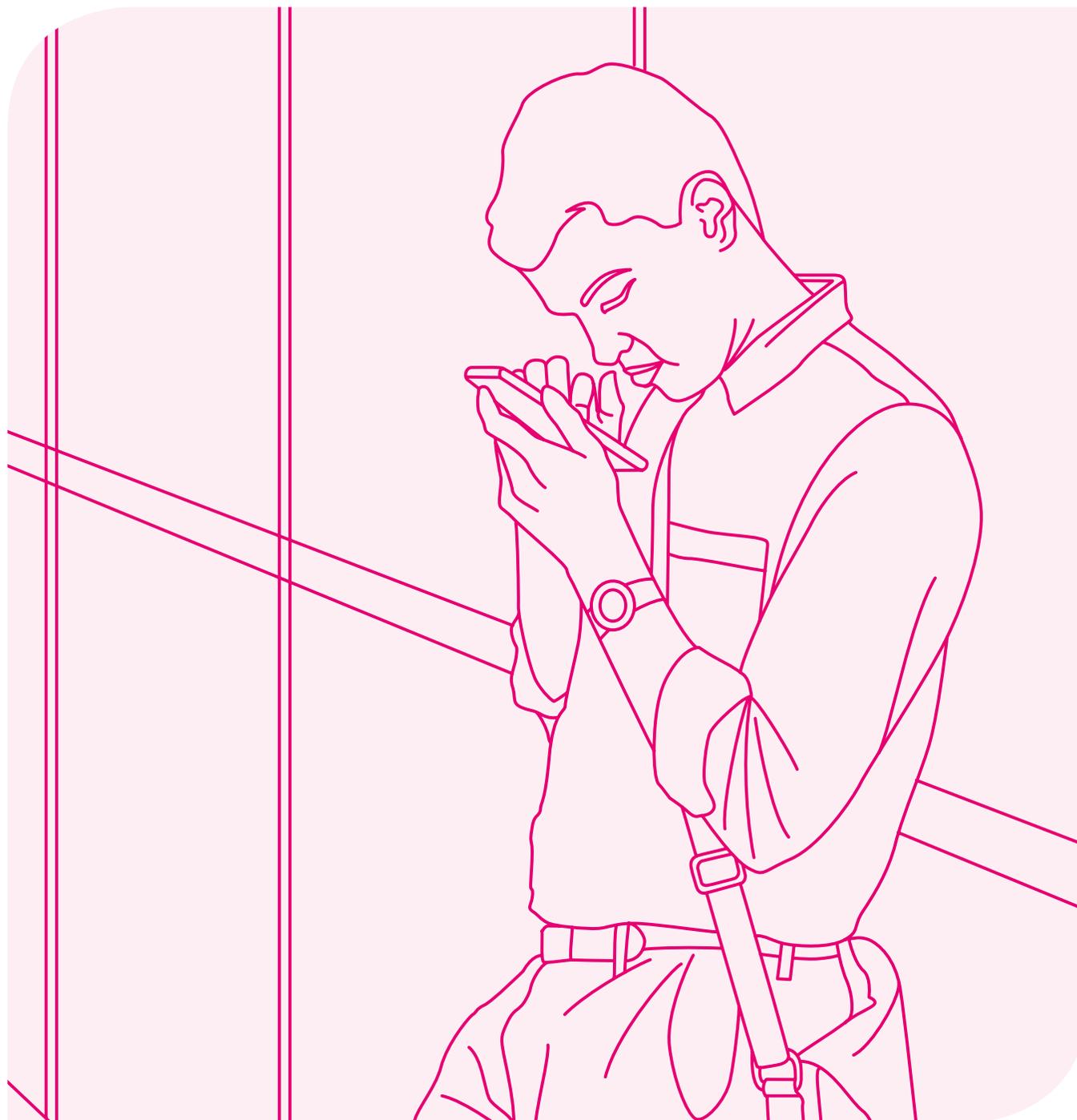
RNIB Evidence-based review

RNIB

Supporting people
with sight loss

Contents

- 3 Introduction
- 4 Profile of children and young people
- 6 Causes and risks of vision impairment
- 7 Services and support
- 12 Case study
- 14 Policy context
- 16 Learning from the evidence base
- 28 References
- 36 About our evidence



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 England. 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.

Profile of children and young people

Population

Vision impairment (VI) in children is a low incidence special educational need and disability (LISEND) which is characterised as follows:

- A need which has the potential to have an adverse impact on learning and development unless additional measures are taken to support the child/young person.
- The prevalence rate is so low that a mainstream setting is unlikely to have sufficient knowledge and experience to meet these requirements. Settings will need to obtain specialist support and advice on how to ensure equitable access and progression (against national standards).

- The prevalence rate is so low that any formula for allocating specialist resources for additional needs, which is based on proxy indicators of need, will not reflect the true distribution of CYP identified as having LISEND [1].

There are an estimated 34,560 CYP aged up to 25 years with a VI of sufficient severity to require specialist support in England. Of these approximately 24,500 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].

According to the Department for Education (DfE) statistics, in January 2015 there was a total of 15,770 pupils in state funded mainstream schools and special schools in England with VI as their primary (main) or secondary special educational need (SEN). Just over two in five (42 per cent) had a statement or Education, Health and Care Plan [7]. This is over 9,500 fewer CYP than on local authority education VI service caseloads in 2014 [8] indicating that DfE figures are an underestimate.

9,535 CYP aged under 18 were registered as blind or partially sighted with social services in England at the end of March 2014 [9].

In the year ending 31 March 2013 a total of 1,280 CYP were issued with a Certificate of Vision Impairment (CVI) by an ophthalmologist to confirm their eligibility for registration

9,535

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

[10]. Registration is voluntary, and while the number of new registrations has increased from 890 in 2011 to 960 in 2014, there is evidence that not all children who are issued with a CVI are subsequently registered by their local authority. In the year 2010/2011 a total of 1,154 child CVIs were issued compared with only 890 registrations [11]. In fact, there is also evidence that not all eligible CYP are issued with a CVI [11].

At least 20 per cent of young people with a VI have additional disabilities and/or special educational needs and a further 30 per cent have multiple and complex needs [12].

There are an estimated

34,560

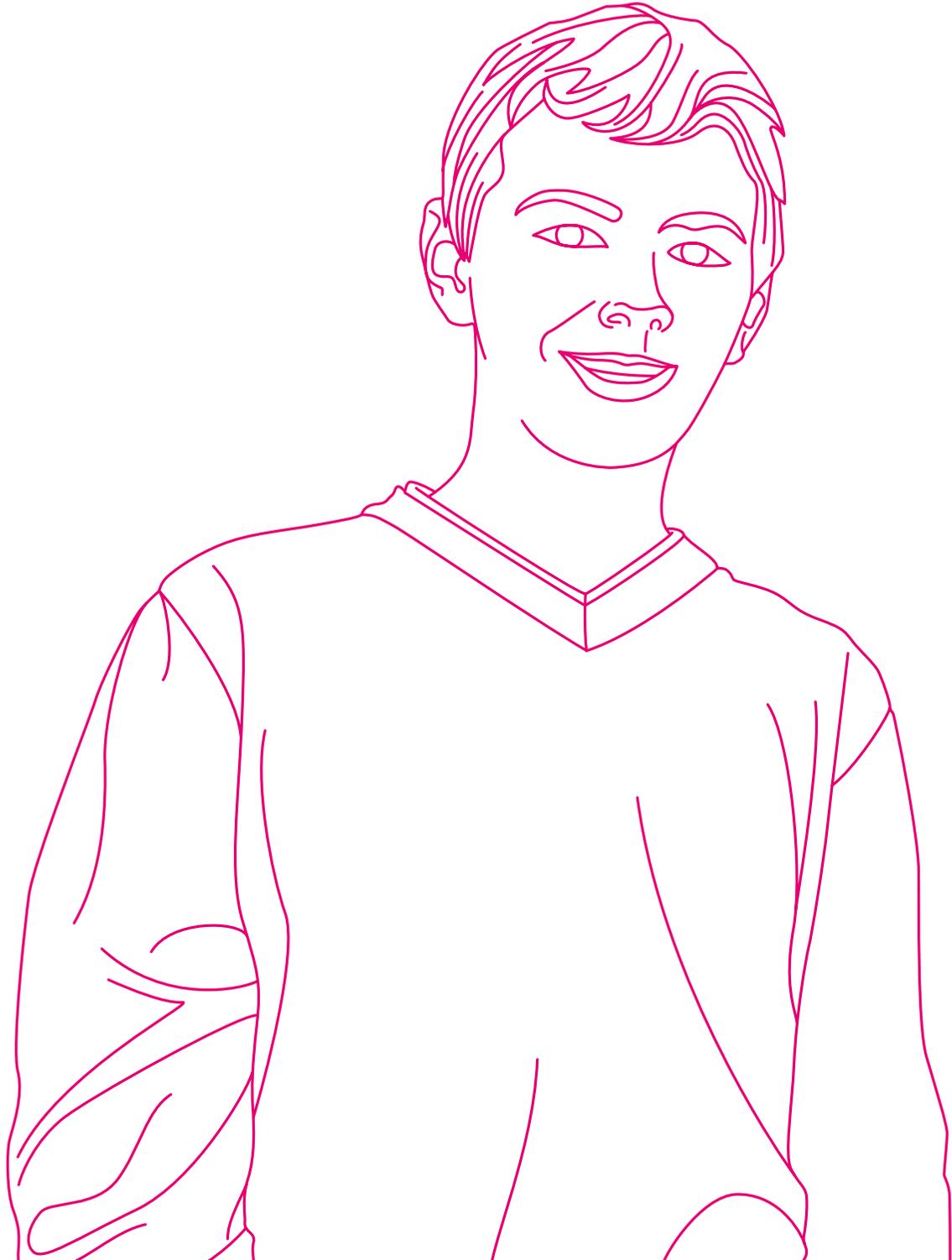
CYP aged up to 25 years with a VI of sufficient severity to require specialist support in England.

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 [13]. The single most common cause of VI in children is cerebral VI. It accounts for up to 48 per cent of blindness and between 32 per cent and 45 per cent of all VI in children [14; 15].

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 [13; 3; 16; 17].

There is a high prevalence of blindness and partial sight in children with learning disabilities (LD) [18].



CYP with LD and VI are currently under represented in official DfE statistics. Research suggests that there are learners in special schools in England whose VI has not been identified [19; 20].

CYP with VI are more likely than children without disabilities or special educational needs to experience social and economic disadvantage [21; 22; 23; 24].

Services and support

Health screening

The UK National Screening Committee 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 [25]:

- 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.

National Institute for Clinical Excellence (NICE) Pathway

A NICE pathway brings together all NICE guidance, quality standards and materials to support implementation on a specific topic area. The pathway – called ‘The Social and emotional wellbeing for CYP’ [26] is particularly relevant for CYP with VI. It brings together recommendations for those involved in promoting social and emotional wellbeing in four areas: strategy, policy and commissioning, early education and childcare, primary education and secondary education.

Education

Approximately two thirds of children who have a VI are educated in mainstream schools, some of which are additionally resourced for learners with VI. Around one third attend special schools for learners with learning

or physical disabilities. Two per cent attend specialist schools designated for blind and partially sighted learners [12].

Young people with VI are well represented in Further Education (FE); in England in 2012/13 a total of 5,600 young people with VI, aged under 19, were undertaking FE and skills training (including apprenticeships) representing 0.5 per cent of all learners in this age range. A further 3,730 were aged 19 to 24 (0.46 per cent). A further breakdown of these figures reveals that 4,360 of these young people were on FE and skills training courses with English and Maths as key components (0.6 per cent of all learners up to the age of 24 on these courses) [27]. These were previously known as ‘Skills for Life’ courses, which are “designed to give people the reading, writing, maths and communication skills they

need in everyday life, to operate effectively in work and to help them succeed on other training courses” [28].

In 2012/13, only 0.35 per cent of young people under the age of 25 on apprenticeships had VI. Success rates for these trainees were slightly lower than for other apprentices: 66 per cent for apprentices with VI aged 19-24 compared with 72.5 per cent of all apprentices in the same age group [27].

In 2013/14 there were 1,040 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 [29].

There are only 12 specialist schools for blind and partially sighted learners in the UK. 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.

There is considerable variation between local authorities in levels of educational provision for learners who have a VI. There is no standard threshold for receiving support from local authority VI services. Variance in provision is increasing and public sector cuts have resulted in continued uncertainty about future staffing and funding in many VI services in England [8].

The specialist practical support that CYP with VI typically require includes the following [30]:

In 2013

2/3

of children who have a visual impairment were educated in mainstream schools

- regular input from a qualified teacher of learners with VI (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 [12].

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. Around 4 per cent of CYP with VI in England use braille as their sole or main literacy format [31]. 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 [32].

Social care

Although the local authority VI education service typically takes the lead role in provision of specialist support for blind and partially sighted CYP, 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) provides practical and financial benefits. Further information can be found here:

<http://www.rnib.org.uk/eye-health/registering-your-sight-loss>

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 [11].

Key professionals

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

- Qualified teachers of learners with VI (QTVI) 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.

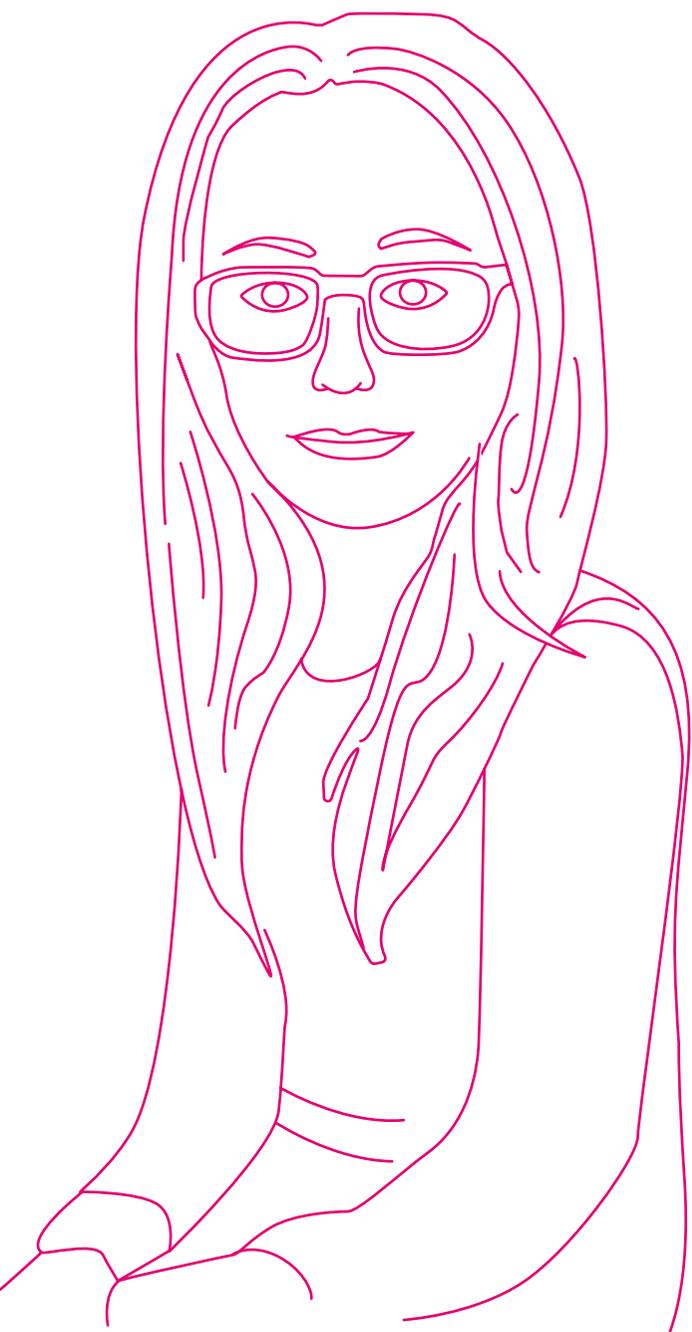
- A Registered Qualified Habilitation Specialist (RQHS) or mobility teacher/habilitation worker should be available to teach CYP how to move around more independently and how to do practical everyday tasks for themselves. All CYP with VI will

require an initial assessment of their mobility and independence needs carried out by a RQHS 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 [33].

- Teaching assistants (TAs) provide in-class and curriculum support. Some TAs are employed by local authority VI services but most are employed by individual settings. 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.

RNIB's 'Best of Both' series [34] of publications describes how QTVIs and other professionals such as physiotherapists and occupational therapists can work together to achieve the best outcomes for children with VI and multiple needs.



Case study

Tiri Hughes, aged 17

Tiri was born partially sighted and also has a connective tissue disorder which causes her limbs to bend more than usual. She can read large print up close but has limited distance vision.

Tiri recently left mainstream school with 10 A star GCSEs. She is now studying for four A levels at the Royal National College for the Blind in Hereford. She is also working towards her Grade 8 Piano. Tiri wants to study medicine when she finishes school.

She is a member of the Great Britain Women's Disability Artistic Gymnastics Squad, and has won several gold medals in her category at the British and

Welsh Open Championships. She also travelled to South Africa for 10 days this year with British Gymnastics on a tour promoting Disability Gymnastics throughout the country.

Tiri is a keen campaigner and volunteer for RNIB, and has even spoken at a reception at the House of Lords about her sight loss.

Tiri lives at home with her parents and younger (sighted) brother Tom. She receives Disability Living Allowance which helps with her mobility and care.

Tiri uses a white cane to get around. She uses a Macbook with a screen reader and also an iPad and iPhone.

By chance, Tiri's mother, Laura used to volunteer for the RNIB Transcription Service. She then had Tiri who was born partially sighted and subsequently knew a lot more about how to access sight loss services than the average new parent.

Laura's biggest concern is that services for blind and partially sighted children and young people are too 'hit and miss'. Laura said: "Services offered are increasingly erratic. The key statutory services of education, mobility/habilitation and health care are a post code lottery and there is no national framework to ensure good provision throughout the UK."

Laura thinks Tiri's biggest achievement is her ability to live her life despite her sight problems. She does things that fully sighted people don't do and is continuing to challenge herself.

Tiri is also a big fundraiser and has raised over £1000 for VI schools in the UK and an orphanage in China that looks after children with sight loss.



“Services offered are increasingly erratic. The key statutory services of education, mobility/habilitation and health care are a post code lottery and there is no national framework to ensure good provision throughout the UK.”

Policy context

It is against the law (Equality Act 2010) [35] 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, including academies and free schools in England, and further/higher education. The Equality Act 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.

Key policy documents and reviews affecting the lives of blind and partially sighted CYP in England include the following:

1989 The United Nations Convention on the Rights of the Child (UNCRC) is an international human rights treaty which was ratified by the UK in 1991. It grants all CYP aged 17 and under a comprehensive set of rights. These include the right to access services such as education and health care [36].

2004 The Children Act 2004 amended the Children Act 1989, stating that the interests of CYP are paramount in all considerations of welfare and safeguarding. The amended act specifically includes provision for disabled children [37].

2012 The Health and Social Care Act established the tackling of health inequalities as a key goal to improve the health outcomes of CYP [38].

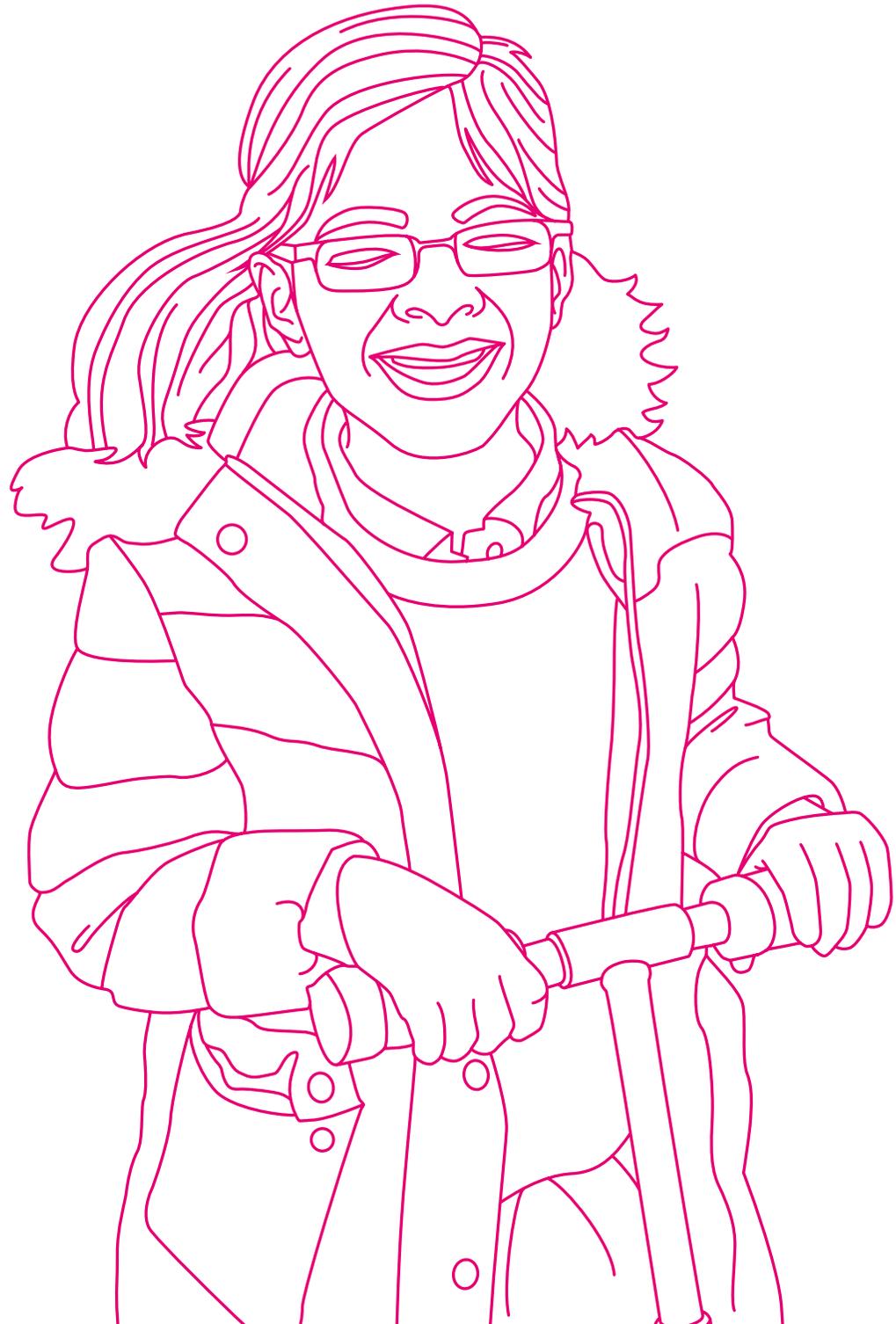
2014 The Children and Families Act and its Code of Practice established a single statutory assessment process and a single education, health and care plan for CYP with SEND from birth to 25 years [39].

2014 The Care Act supports young people, who reach the age of 18, in moving from children's to adult care to ensure that there is no gap in services [40].

Since education has been devolved, the education contexts are becoming increasingly divergent in the four UK countries. However, although some policies differ across the UK, common issues are evident and some common themes are emerging:

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.



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; 17; 11].

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 a 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].



If babies with a 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].

Emotional wellbeing and social relationships

At age seven, children with VI in the Millennium Cohort Survey (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. [21]. 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 [24].

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 [21; 24].

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 [21; 24]. 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 [24].



Blind children, in particular, require high levels of specialist input to address crucial needs in their cognitive development, communication, social and independence skills [46].

CYP with VI are regular users of information technology including mobile phones, and communicate regularly through social networking sites such as Facebook [48; 24]. However, this is less likely to be the case for children with VI and additional SEND [24]. CYP with VI are also interested in a wide range of leisure activities [29; 24]. At the age of eleven, however, there is some evidence to suggest that they are less physically active than other children [24].

Children aged seven with VI in the MCS were just as likely as fully sighted children to say they had “lots” of good friends [21], 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 [24]. 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 [21; 24].



Children aged seven with VI in the MCS were just as likely as fully sighted children to say they had “lots” of good friends.

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 [23; 22; 24]. 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 [24].

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 [51] 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 [52]. 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 [53; 54].

Key longer term independence skills (including mobility and social skills) that fall beyond the academic curriculum may be neglected [55; 54; 56; 57].

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 [58]. Evidence indicates that TAs can best support children with VI if they have an understanding of VI and how it affects the individual [55]. RNIB has identified over 2,400 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 [8; 31].

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 [59]. 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 [60].

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 [8].

Transition to further study, training and employment

Ofsted, has reported on the local variations in availability and quality of post-school provision for those with specialist needs such as sensory impairment [61]. 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 [62].



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 [64].

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) [53; 63]. 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 [54; 56].

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 [64]. 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 [65].

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

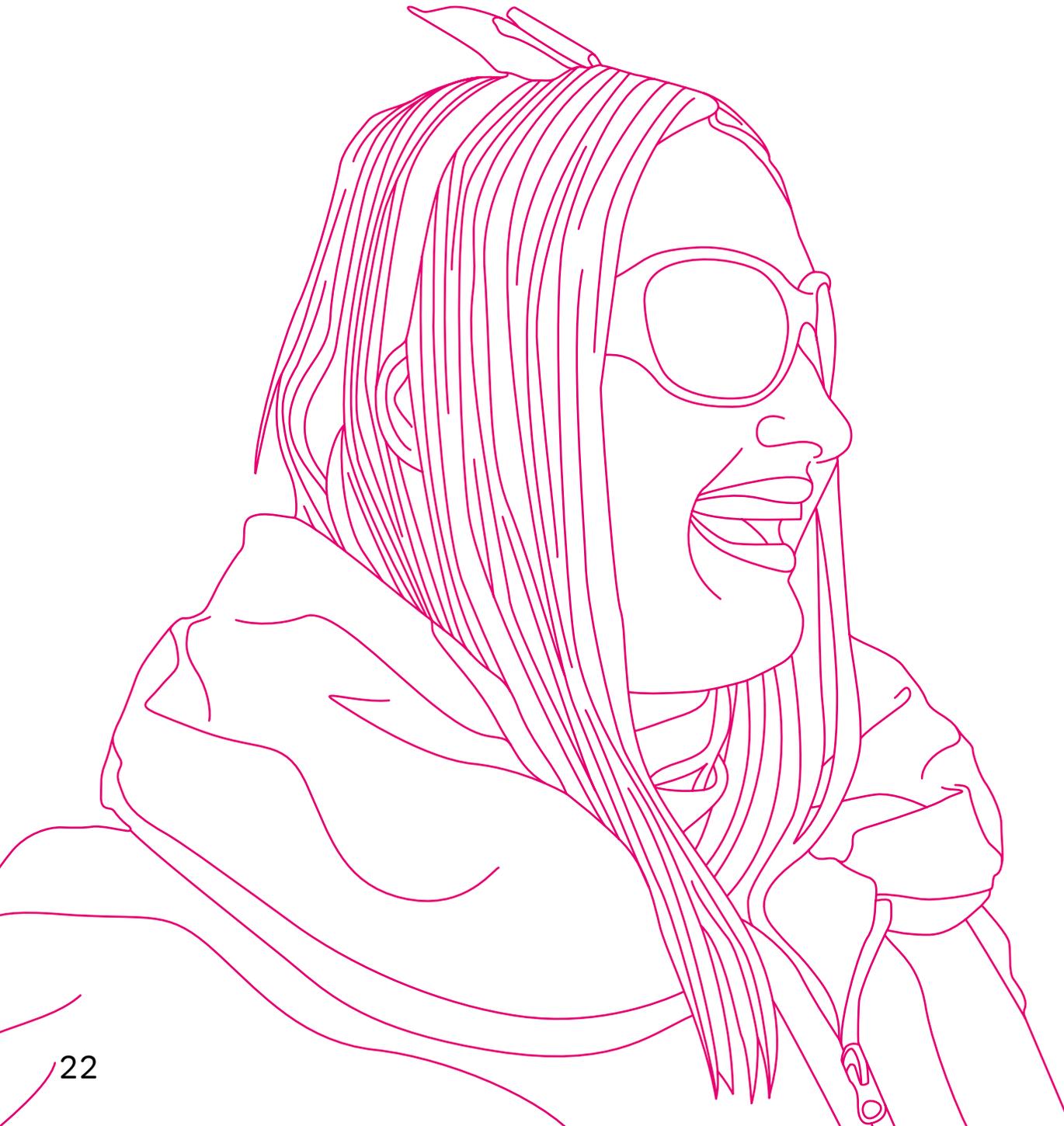
Factors that contribute to successful transition of young people with complex needs from residential school provision include:

- 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 [66; 67].

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) [68].

For blind and partially sighted people, holding an educational qualification is a key enabler for obtaining employment [55]. In addition to employers’ attitudes, factors that determine a blind or partially sighted person’s distance from the labour market,



In 2013

38.9%

of graduates with VI found
full time employment

and whether they are ready for work, are detailed in the Evidence-based review of people of working age [69]. 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 [70]. 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; 71].

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 [72].

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

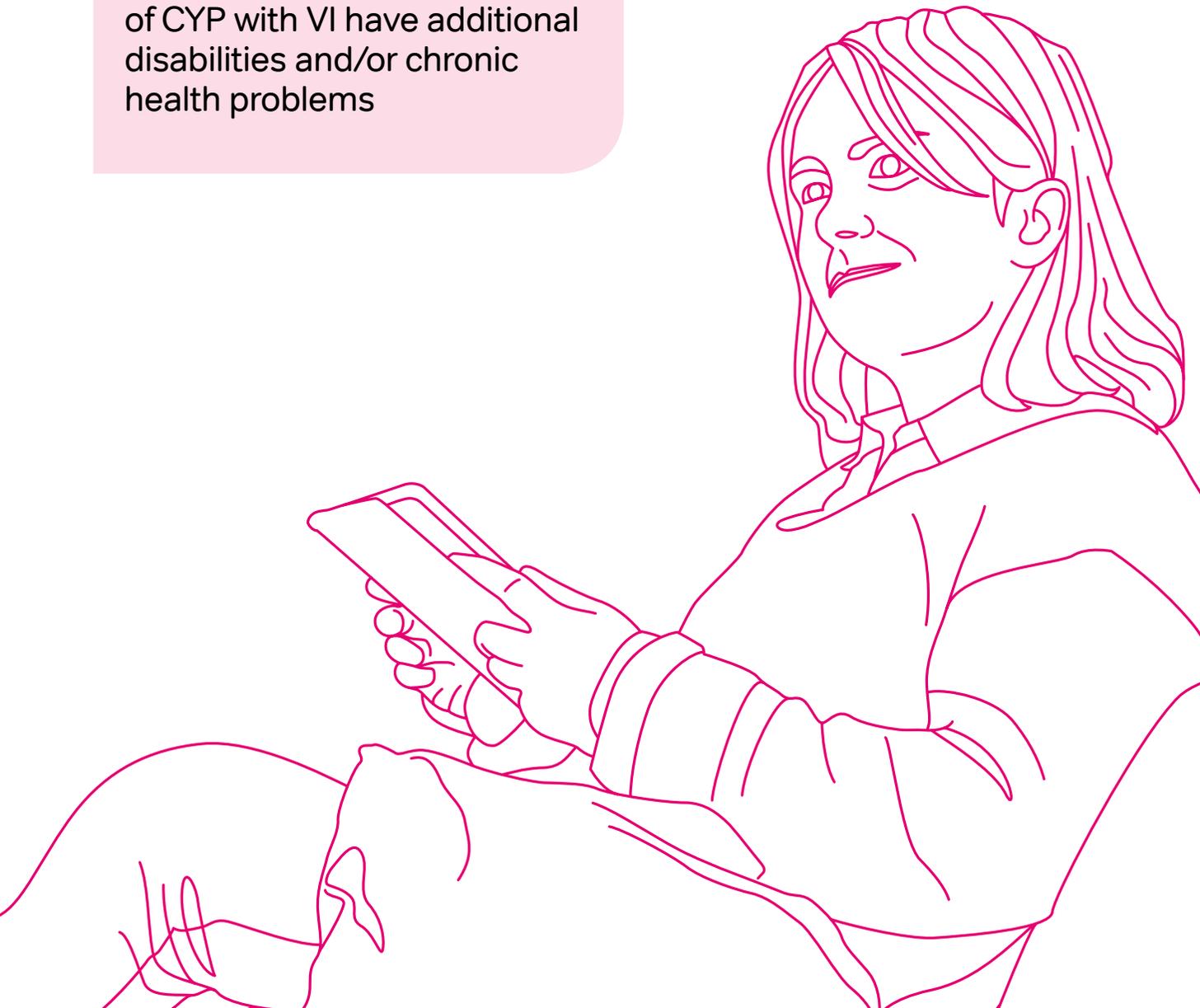
- Unlike adults, most children with VI have conditions that are present from birth or diagnosed in the first year of life. Professionals supporting babies and young children and their families should have specialist training in childhood VI and should be encouraged to use the Developmental Journal for Babies and Children with Visual Impairment [73]. 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. Vision2020 UK has a recommended pathway for CYP with VI [74]. See also Boyce, 2015 [11] and Boyce et al, 2015 [75] for a wider discussion about pathways.
- 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.

At least

50%

of CYP with VI have additional disabilities and/or chronic health problems



- 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.
- Parents of children who are registered say that registration is important to them, yet there is evidence that not all local authorities 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 [11].



Parent carers, mainstream education and specialist support all have a role to play in providing social skills and independence training to CYP with VI.

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 [76].



- Parent carers, mainstream education and specialist support all have a role to play in providing social skills and independence training to CYP with VI.

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
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 and Hill (2003) 'Visual impairment in childhood: insights from a community-based survey' *Child: Care, Health and Development* 2003, Vol 29, Pt 6, pp 493 – 499.
6. Bone and Meltzer (1989) *OPCS surveys of disability in Great Britain Report 3: The prevalence of disability among children London: HMSO.*
7. Department for Education (2015) *Special educational needs in England: January 2015. Statistical First Release*
gov.uk/government/statistics/special-educational-needs-in-england-january-2015
8. 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.*
9. Health and Social Care Information Centre (2014) *Registered blind and partially sighted people. Year ending 31 March 2014, England.*
hscic.gov.uk/catalogue/PUB14798
10. RNIB (2014) *Number of adults and children certified with sight impairment and severe sight impairment in England and Wales: April 2012 to March 2013. RNIB.*
11. Boyce (2015) *Ensuring Support: Certification and Registration in CYP with VI in England. Report commissioned by RNIB.*

12. Keil (2012) RNIB survey of VI services in England and Wales 2012: Report for England. RNIB.
13. Rahi and Cable (2003) 'Severe visual impairment and blindness in children in the UK' The Lancet, Vol 362, Oct 25, 2003.
14. Mitry, Bunce, Wormald, and Bowman (2013) 'Childhood VI in England: a rising trend'. Archives of Disease in Childhood 2013; 98: 378-380.
15. 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.
16. 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.
17. Solebo and Rahi (2014) Epidemiology, aetiology and management of visual impairment in children. Arch Dis Child 2014, 99: 375-379.
18. Das, Spowart, et al. (2010) 'Evidence that children with special needs all require visual assessment.' Archives of Disease in Childhood 95(11): 888-892.
19. 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.
20. Bunce (2012) Visual Impairment in special schools in the UK. Unpublished report for RNIB.
21. Harris, Keil, Lord and McManus (2012) Sight impaired at age seven: Secondary analysis of the Millenium Cohort Study. RLSB, RNIB and NatCen Social Research.
22. Bassett (2010) Educational progress of young blind and partially sighted pupils. Statsconsultancy for RNIB.
23. Chanfreau and Cebulla (2009) Educational attainment of blind and partially sighted pupils. National Centre for Social Research (NatCen) for RNIB.

24. Harris, Keil, Lord and Lloyd (2014) Sight impairment at age eleven: Secondary analysis of the Millennium Cohort Survey. RLSB, RNIB and NatCen Social Research.
25. Hall and Elliman (2006) Health for all Children. OUP Oxford; New ed of 4 Revised ed edition.
26. NICE (2015) Social and emotional wellbeing for CYP pathways.nice.org.uk/pathways/social-and-emotional-wellbeing-for-children-and-young-people
27. Skills Funding Agency (2014) Equality and Diversity Report 2008 to 2009 and 2012 to 2013 and Equality and Diversity Tables gov.uk/government/statistical-data-sets/fe-data-library-equality-and-diversity
28. Skills Fund Agency(2015) Statistical First Release: Further Education and Skills: Learner Participation, Outcomes and Level of Highest Qualification Held. June 2015.
29. Higher Education Statistics Agency (2015) hesa.ac.uk/content/view/1973/239/
30. Department for Education and Skills (2002) Quality Standards in Education Support Services for CYP with Visual Impairment webarchive.nationalarchives.gov.uk/20081230134948/http://www.teachernet.gov.uk/_doc/6576/quality%20standards%20-%20visual%20impair.htm
31. Keil (2016) Report on findings from RNIB Freedom of Information (FOI) requests 2015. Awaiting publication.
32. Pring (2004) (Ed) Autism and blindness: Research and reflections. Wiley.
33. Department for Children, Schools and Families (2011) Quality Standards: Delivery of Habilitation Training (Mobility and Independent Living Skills) for CYP with Visual Impairment rnib.org.uk/sites/default/files/qs_for_the_delivery_of_habilitation_training.pdf
34. RNIB Best of Both guides rnib.org.uk/services-we-offer/advice-professionals/education-professionals/complexneeds

35. Equality Act (2010)
**legislation.gov.uk/
ukpga/2010/15/contents**
36. The United Nations
Convention on the Rights of
the Child 1989
**unicef.org.uk/UNICEFs-
Work/UN-Convention/**
For information on how
the Act protects blind and
partially sighted people
please visit:
rnib.org.uk/equalityact
37. The Children Act 2004
**legislation.gov.uk/
ukpga/2004/31/contents**
38. The Health and Social Care
Act 2012
**legislation.gov.uk/
ukpga/2012/7/contents**
39. The Children and Families
Act 2014
**legislation.gov.uk/
ukpga/2014/6/contents**
40. The Care Act 2014
<http://www.legislation.gov.uk/ukpga/2014/23/contents>
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. RNIB.
43. O'Reilly, Sakkalou, Sakki, Dale, Salt, Dale (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. Keil, Parris, Cobb, Edwards and McAllister (2006). Too little, too late: Provision of textbooks to blind and partially sighted children. RNIB.
52. Khadka (2010) Development of the Cardiff Visual Ability Questionnaire for CYP (unpublished PhD dissertation), School of Optometry and Vision Science, University of Cardiff.
53. 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.
54. Hewett R (2015) Learning to be independent in school and college. Presentation at RNIB and University of Birmingham national transitions conference, 1 July 2015
rnib.org.uk/transitionconference

55. 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.
56. 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
www.rnib.org.uk/transitionconference
57. 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.
58. Blatchford, Russell and Webster (2012) Reassessing the impact of teaching assistants: How research challenges practice and policy. Routledge: London.
59. 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.
60. 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.
61. Ofsted (2011) Progression post-16 for learners with learning difficulties and/or disabilities. Ofsted (August 2011) Reference no: 100232.
62. 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.

63. 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 rnib.org.uk/transitionconference
64. Trief and Feeney (2003) 'Guidelines for a pre-college curriculum for students with blindness and visual impairments' RE:view, 35(3), 137.
65. 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 rnib.org.uk/transitionconference
66. 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.
67. 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.
68. 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.
69. RNIB (2016) Evidence-based review: People of working age. RNIB
70. 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.

71. Douglas (2015) Finding Work. Presentation at RNIB and University of Birmingham national transitions conference, 1 July 2015
www.rnib.org.uk/transitionconference
72. AGCAS (2015) What happens next? A report on the first destinations of 2013 disabled graduates. AGCAS Disability Task Group. June 2015.
73. Developmental Journal for Babies and Children with Visual Impairment
councilfordisabledchildren.org.uk/what-we-do/our-networks/early-support/early-support-resources
74. 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/>
75. Boyce, Dahlmann-Noor, Bowman, Keil (2015) 'Support for infants and young people with sight loss: a qualitative study of sight impairment certification and referral to education and social care services' BMJ Open 2015;5:e009622 doi:10.1136/bmjopen-2015-009622
76. Department for Education (2015) Special educational needs and disability code of practice: 0-25 years. Crown Copyright.

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:

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

.....

.....

National Helpline 0303 123 9999
helpline@rnib.org.uk

 **facebook.com/rnibuk**

 **twitter.com/RNIB**

 **youtube.com/user/rnibuk**

© 2016 RNIB
Registered charity numbers 226227
(England and Wales), SC039316 (Scotland)

rnib.org.uk

