

Children and young people Scotland

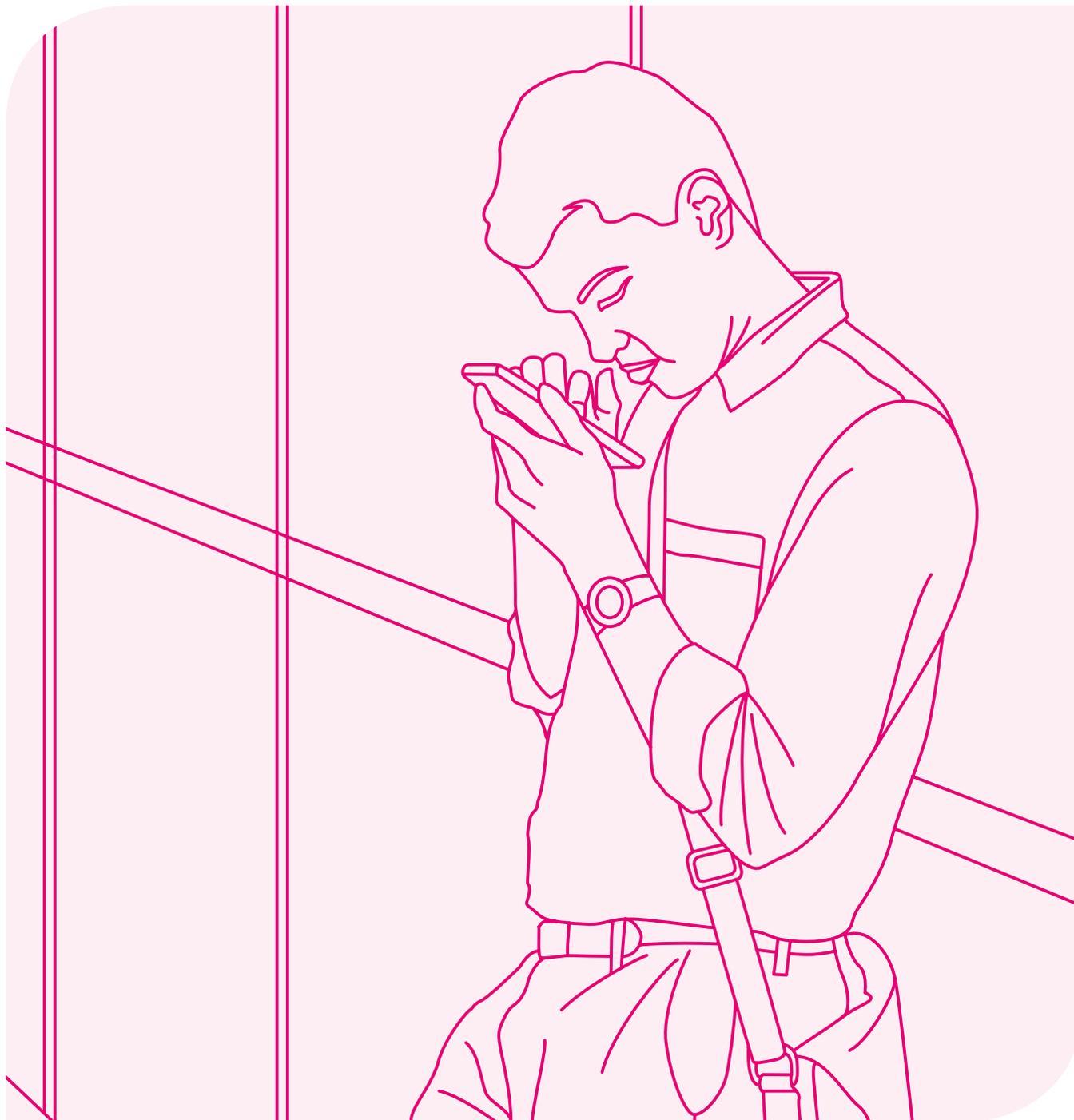
RNIB Evidence-based review

RNIB
Scotland

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 Scotland. 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. It also recognises the different approach to multi professional delivery through Getting it right for every child (GIRFEC) and reference is made to Additional Support Needs (ASN) rather than Special Educational Needs (SEN) which is used elsewhere in the UK.

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 3,219 CYP aged up to 25 years with a VI of sufficient severity to require specialist support in Scotland. Of these approximately 2,200 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 additional support needs– can have implications for the child’s learning and development [3;4;5; 6].

- At least 20 per cent of young people with a VI have an additional support need and a further 30 per cent have multiple and complex needs [7].

Causes and risks of vision impairment

Wider research shows that 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 [8]. 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 [9; 10].

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 [8; 3; 11; 12].

There is a high prevalence of blindness and partial sight in children with learning disabilities (LD) [13].

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Children and young people aged under 18 were registered as blind or partially sighted with social services in Wales at the end of March 2014

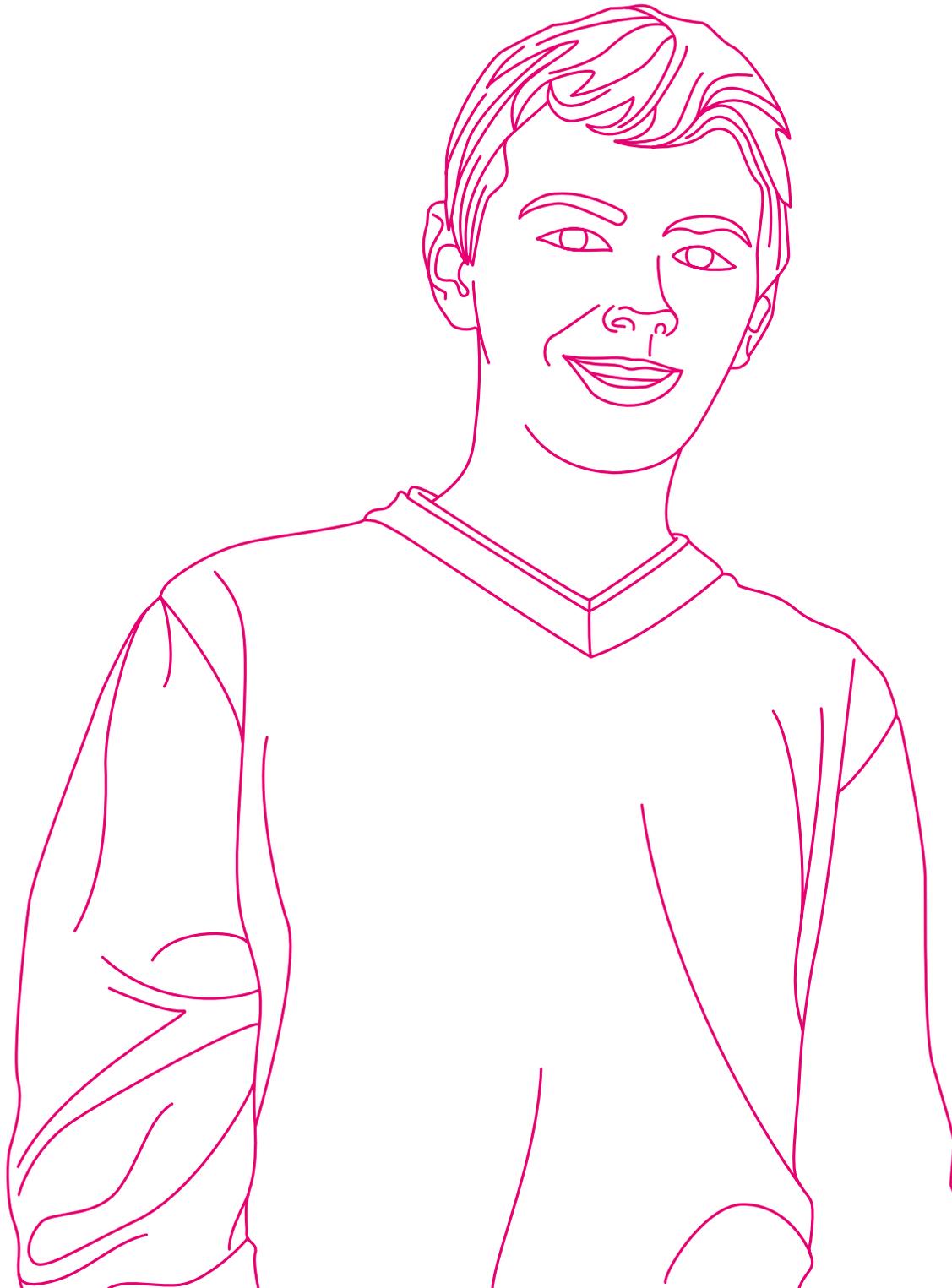
CYP in England with LD and VI are currently under represented in official Department for Education (DfE) statistics. Research suggests that there are learners in special schools in the UK whose VI has not been identified [14; 15].

CYP with VI are more likely than children without disabilities or special educational needs (SEN) to experience social and economic disadvantage [16; 17; 18].

At least

20 per cent

of young people with a VI have additional disabilities and/or special educational needs



Services and support

Health screening

Visual Impairment Network for Children and Young People (VINCYP) is a managed clinical network which is developing a data framework for referral pathways across Scotland for CYP which includes improved screening, diagnosis, early intervention and appropriate referral routes outside the eye clinic.

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 [19]:

- 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

Since 2004 there has been the presumption of mainstreaming in education. Most VI pupils go to their local school. More than 70 per cent of school-aged children with VI were educated in mainstream primary and secondary schools; around 16 per cent were placed in special schools and around 10 per cent in specialist units [20].

Young people with VI are reasonably well represented in Further Education (FE) and Higher Education (HE) in Scotland. In 2010-11 there were 120 FE students with VI, and 405 HE students with VI [21].

There are currently no figures of people with VI in modern apprenticeships. However less than 0.5 per cent of all modern apprenticeship placements are taken by someone with a declared disability. Around 8 per cent of the target population (16-24) is disabled [22].

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 Scotland.

The Requirements for Teachers (Scotland) Regulations 2005 (Scottish Statutory Instrument 2005/355) [23] came into force in September 2005. The Regulations state that where an education authority employs a teacher wholly or mainly to teach pupils who are hearing impaired, vision impaired or both hearing and vision impaired, then that teacher must possess an appropriate qualification to teach such pupils.

In Scotland, VI teachers have traditionally completed a postgraduate diploma at a higher education institute. However, the recent guidelines have advised that a more flexible approach to qualification is required, and competence-based routes to a postgraduate qualification are now available. It is expected that all teachers working with pupils who have a sensory impairment within Scotland will be appropriately qualified within five years of taking up post. This is not happening in all areas with inexperienced teachers delivering support to many pupils.

The 2012 study, *The Education of Children and Young People with a Sensory Impairment in Scotland* reported that there were a total of 88 specialist VI teachers working across 27 authorities that responded to their survey. Nearly 60 per cent of these were aged 45 or over. Funding, lack of time, commitment by staff,

staff cover and distance from the provision were identified as key challenges in relation to ensuring that specialist VI teachers were fully qualified. There is also no financial incentive for teachers to obtain this additional qualification or to adopt this specialist role. [20]. These challenges are more pronounced in today's climate of austerity and local government cutbacks.

The specialist practical support that CYP with VI typically require includes the following [24]:

- regular input from a Qualified Teacher of learners with Vision Impairment (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 [7].

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. Wider evidence shows that around four per cent of CYP with VI use braille as their sole or main literacy format [25]. 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 ASN 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 [26].

Social care

In Scotland, under the Education (Additional Support for Learning) Act there is no need for a child or young person to be registered as severely sight impaired (blind) and / or sight impaired (partially sighted) to receive appropriate support. However, parents of children who are registered in England say that registration is important to them, and they see the value of it to safeguard input from social care. This 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 [27].

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:

- 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 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 specialist working in partnership with parents and the QTVI. National standards and training for habilitation specialists 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 [28]. These standards are being pursued across service providers in Scotland. Currently in Scotland habilitation is provided either through local authority social work / education teams; or by local societies and more recently by Blind Children UK.

- Additional Support Needs Assistants provide in-class and curriculum support. They are all employed by local authorities. Although there is no statutory requirement for Additional Support Needs Assistants to have specialist training, it is encouraged.
- 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 (Equality Act 2010) [29] 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 Equality Act includes a duty to make reasonable adjustments, including the provision of auxiliary aids where these are not currently provided. 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 through the GIRFEC pathway.

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 Scotland include the following:

2004 Education (Additional Support for Learning) Act [30].

2009 Update to the Education (Additional Support for Learning) Act extended the duty of care to non-educational providers such as Health, Social Work, Skills Development Scotland [31].

2012 Getting it Right for Every Child updated to improve collaborative practice for multi-professional assessment and service delivery and establish a 'named person' to oversee the support provided to any child with additional support needs within a local authority [32].

2013 Growing up in Scotland – a longitudinal research study tracking the lives of thousands of children and their families from the early years, through childhood and beyond. Recent report 'The impact of disability on the lives of young children' [33].

2014 CYP (Scotland) Act introduces a 'named person' to oversee the support provided to all children. This will be especially relevant to children with additional support needs within a local authority [34].

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

Billy Hendren

Billy was born with myopia (nearsightedness) and nystagmus. He has had laser treatment but it didn't help. He has been registered partially sighted and has peripheral vision which has got worse over the years. He now has no sight in his right eye at all. In addition to his laser treatment he has also had five brain operations which have affected his sight too.

Billy lives just outside Glasgow in a small village which is quite rural. It has a handful of shops and he says it has been difficult to walk around sometimes, though he has got used to it and has routes he knows and feels comfortable with.

Billy admits struggling at times with his eyes. "My sight loss combined with my other health problems does mean that it is difficult for me to go out with friends and there are a lot of events and things that I can't go to." However he says he has a best friend from primary school who he sees often.

Billy is too young to be fully independent and still lives at home. He receives Disability Living Allowance (DLA). Billy says: "I use my DLA to buy things like clothes, books or to save up for when we go on holiday. As I can't get a job then I really need this money to be able to pay for things like other teenagers and I don't always want to have to ask my mum for money.

“It helps me stay independent and if it is reduced, I don’t know what I will do.”

Billy’s mum has spoken about a potential reduction in benefits: “DLA allows William to have some independence that he wouldn’t otherwise have. To take this away from him and from other people in the same situation is diabolical. They didn’t choose to be born this way.”

Billy is going to college to study Business with Accounting. He will be living at home with his family.

“My mum is amazing and does a lot for me. My parents give me a lot of lifts to places and will always come and help me if I need them to”.

When he goes to college he will have a sight impairment worker to help him.

“I have other health problems which mean I have to be very careful when I’m out and about and need someone to be with me at all times. I do use a symbol cane but not at school because that is a familiar place for me”.

Growing up Billy used large print books from RNIB and says the school library was very helpful in setting things up for him. Billy enjoys playing video games and can do so from the sight in his left eye. He also has an interest in and collects model buses lorries.

Billy is an active member of his church and acts as an acolyte in his local catholic church. He is thinking of being a priest when he is older.



“I have other health problems which mean I have to be very careful when I’m out and about and need someone to be with me at all times. I do use a symbol cane but not at school because that is a familiar place for me”.

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 [35]. 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 [35].

Diagnosis and early support

In Scotland a recognition that services for CYP need to be improved at diagnosis and the earliest stages of development has led to the creation of VINCYP. The aim is to improve services across the country.

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 [36; 12; 27]. IRISS (Identify, React, Intervene, Sustained Support) is a new RNIB Scotland project supporting CYP, from birth to 18 years old, and their families in four NHS Health Board areas - Greater Glasgow and Clyde, Ayrshire and Arran, Lanarkshire and Forth Valley. IRISS offers a support package for approximately 12 weeks, providing information on eye conditions, local services and support organisations to improve the lives of the CYP and their families.

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 [35].

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 [37; 38]. 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 [39]. Blind children, in particular, require high levels of specialist input to address crucial needs in their cognitive development, communication, social and independence skills [40].

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Emotional wellbeing and social relationships

Wider research shows that 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 [16]. 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 [18].

Other research has found lower quality of life scores in children with VI [41].

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 [16; 18].

At ages seven and eleven, children with VI plus an additional SEND (Special Education Needs and Disability, England's equivalent of ASN) are at particularly high risk of poor outcomes across a range of emotional and social wellbeing indicators [16; 18]. 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 [18].

CYP with VI are regular users of information technology including mobile phones, and communicate regularly through social networking sites such as Facebook [42; 18]. However, this is less likely to be the case for children with VI and additional SEND [18]. CYP with VI are also interested in a wide range of leisure activities [43; 18]. At the age of eleven however, there is some evidence to suggest that they are less physically active than other children [18].

Children aged seven with VI in the MCS were just as likely as fully sighted children to say they had "lots" of good friends [16], 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 [18]. 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 [42]. 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 [43]. Children of school age with VI have been found to have poorer use of language for social communication than their fully sighted peers [44].

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 [16; 18].

Curriculum access and attainment

There is a clear attainment gap between visually impaired pupils and their sighted peers in Scotland. The Implementation of The Education (Additional Support for Learning) (Scotland) Act 2004 (as amended): Report to Parliament 2013 provided an average tariff score of school leavers representing the overall qualifications a leaver has achieved while at school. The larger the average tariff score, the more the leaver has achieved. The average tariff score for pupils without ASN was 385 in 2009-10; 405 in 2010-11; and 433 in 2011-12. The average tariff score for pupils with visual impairment was 161, 234 and 249 respectively, reflecting the attainment gap [45].

- This finding echoes the conclusion of the 2012 study, The Education of Children and Young People with a Sensory Impairment in Scotland, which

found that pupils with no ASN achieve better national qualifications than those with ASN, and that pupils with a visual impairment are significantly more likely than those with a hearing impairment and some other categories of ASN to achieve no or low qualifications [20].

However, around the same (low) proportion of pupils with a hearing or a visual impairment achieve Highers and Advanced Highers [20].

- Analysis of data relating to school leavers from local authority and grant aided schools in Scotland in 2007 found that school leavers with VI were far less likely than leavers with no ASN to attain five or more Standard Credit Grades (SCQF 5). Several factors were found to affect the educational attainment of pupils with a visual impairment.

These were having ASN (including visual impairment), being male, being disabled, attending a special school, attending a school with a higher percentage of leavers eligible for free school meals, and living in a deprived area [17].

- The Chanfreau and Cebulla research had also found that school leavers with visual impairment in Scotland were more likely than leavers with other types of ASN (treated as a single group) to achieve five or more SCQF grades. This research did not however, distinguish between leavers with visual impairment as their only ASN and those with other types of ASN in addition to a visual impairment. Wider research in England and Wales shows that 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 [17; 46; 18]. 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 [18].

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 [47] 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 [48]. 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 [49; 50].

Key longer term independence skills (including mobility and social skills) that fall beyond the academic curriculum may be neglected [51; 50; 52; 53].

As well as accessing the school curriculum, blind and partially sighted pupils should be involved in the whole life of the school and the wider community. However, this level of social inclusion requires training by habilitation specialists.

Habilitation takes a holistic approach, with an emphasis on the early development needs of children with visual impairments. However, at the moment, habilitation provision is fragmented whilst it is also delivered in very different ways across Scotland. There are few qualified habilitation specialists with the two-year qualification in habilitation run only in London and Birmingham. There is no equivalent course on offer in Scotland at the moment.

The lack of a standardised habilitation service in Scotland is likely to have an impact on the educational attainment of VI pupils.

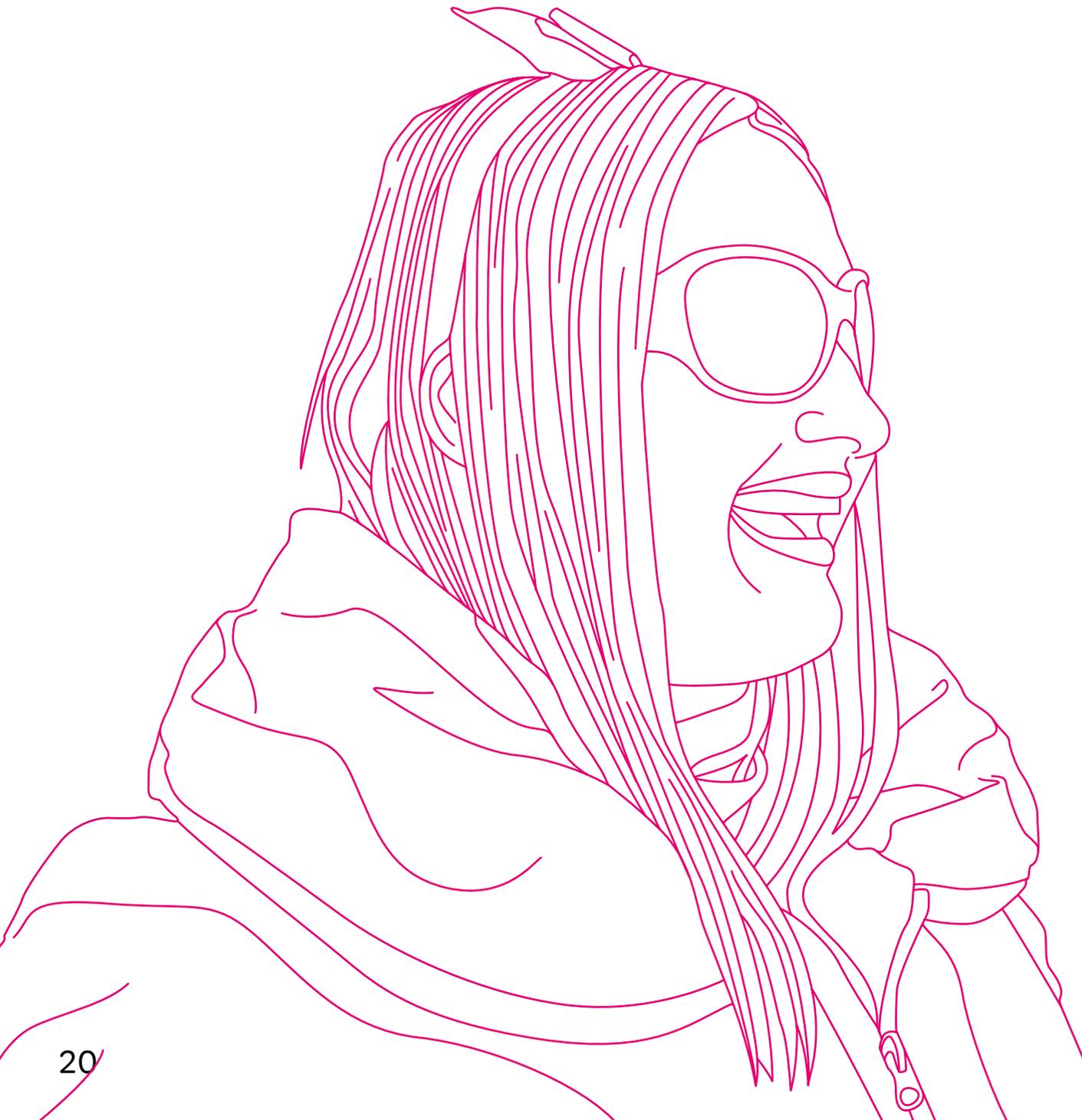
Wider research shows that although Teaching Assistants (TAs: England's equivalent of Additional Support Needs Assistants) play an important role, evidence relating to pupils with SEN (but not VI) shows that they may also prevent social inclusion and have an adverse effect on educational attainment by acting as a barrier between the child, their peers, and their teacher [54]. Evidence indicates that TAs can best support children with VI if they have an understanding of VI and how it affects the individual [51].

This is a matter of concern as it indicates that these TAs may be working without the supervision of a QTVI from the local authority VI service [55].

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 [56]. 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 [57].

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 [55].



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 [58].

A Scottish Government report [20] suggests that many young people living with sight loss are not achieving their full potential when compared with other disabled and able-bodied peers. Skills Development Scotland data also informs us that a relatively high proportion of pupils with sight loss will achieve low or no qualifications compared to those without sight loss [59].

If we compare school leavers with a sight loss condition with leavers who have no ASNs,

the data demonstrates that, for young people with sight loss, they will achieve fewer academic qualifications at secondary school than pupils without an ASN [59].

The data informs us that school leavers with sight loss are less likely to be in employment (93 per cent difference), attend university (50 per cent difference) or both seeking (80 per cent difference) and not seeking employment (160 per cent difference) compared to school leavers without additional support needs. They are however more likely to be attending a further education course (48 per cent difference). The data for those entering some form of training is extremely small with less than five per cent of school leavers with sight loss entering a training programme including modern apprenticeships [59].

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) [49; 60].

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 [50; 52].

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 [61]. 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 [62].

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 [63; 64].

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) [65].

For blind and partially sighted people, holding an educational qualification is a key enabler for obtaining employment [51]. 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 [66]. 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 [67]. 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 [43; 68].

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 [69].

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 [70].
- 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 [71]. See also Boyce, 2015 [27] and VINCYP pathway [72].

- 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.

- All children are vision screened in reception aged 4-5 years but children attending special schools require much more in-depth and specialist assessment of their functional 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 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 [27].

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.

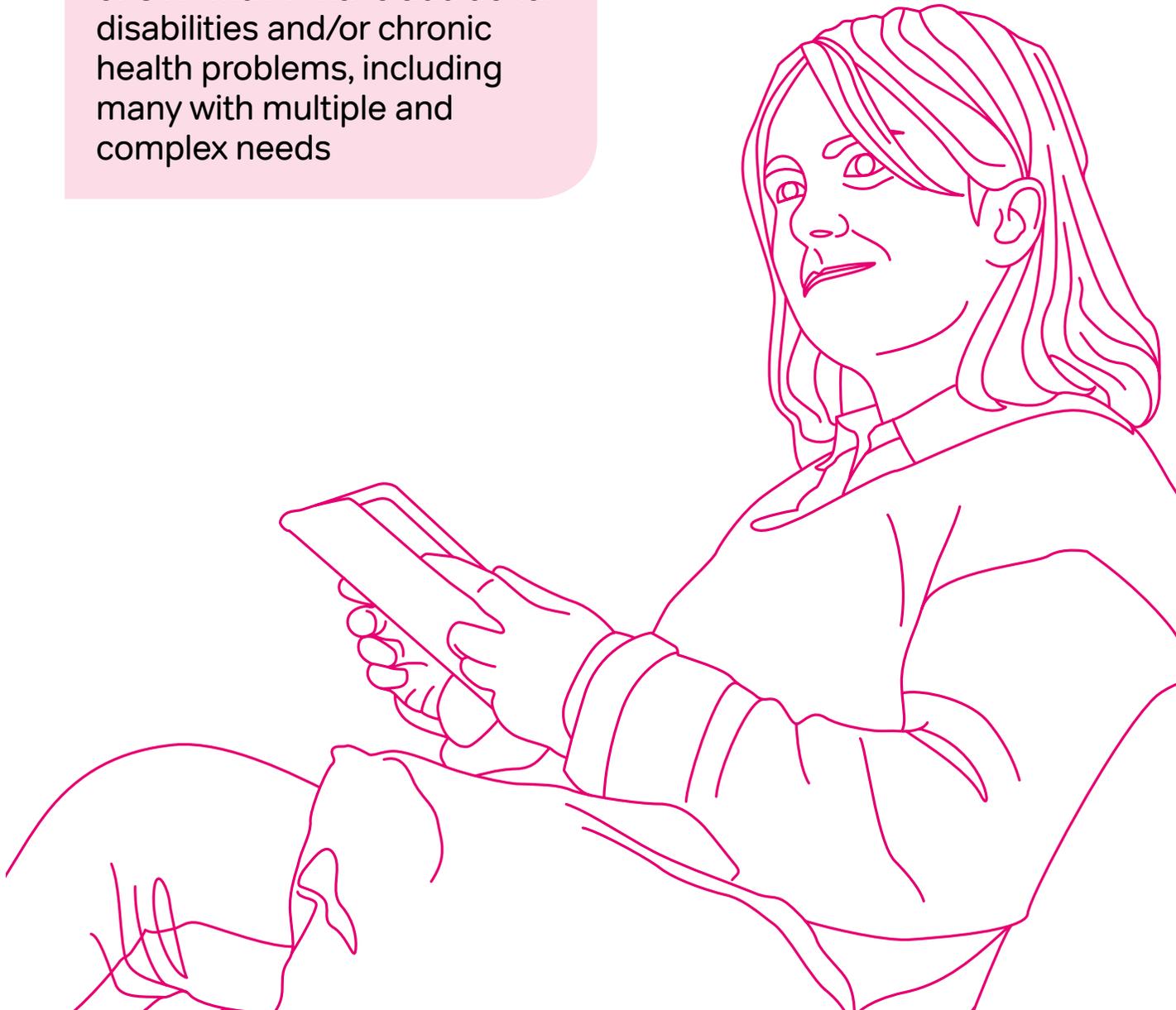
All CYP with VI are entitled to a full assessment by a registered qualified habilitation specialist, with education and habilitation provision in accordance with their assessed need.

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

At least

50%

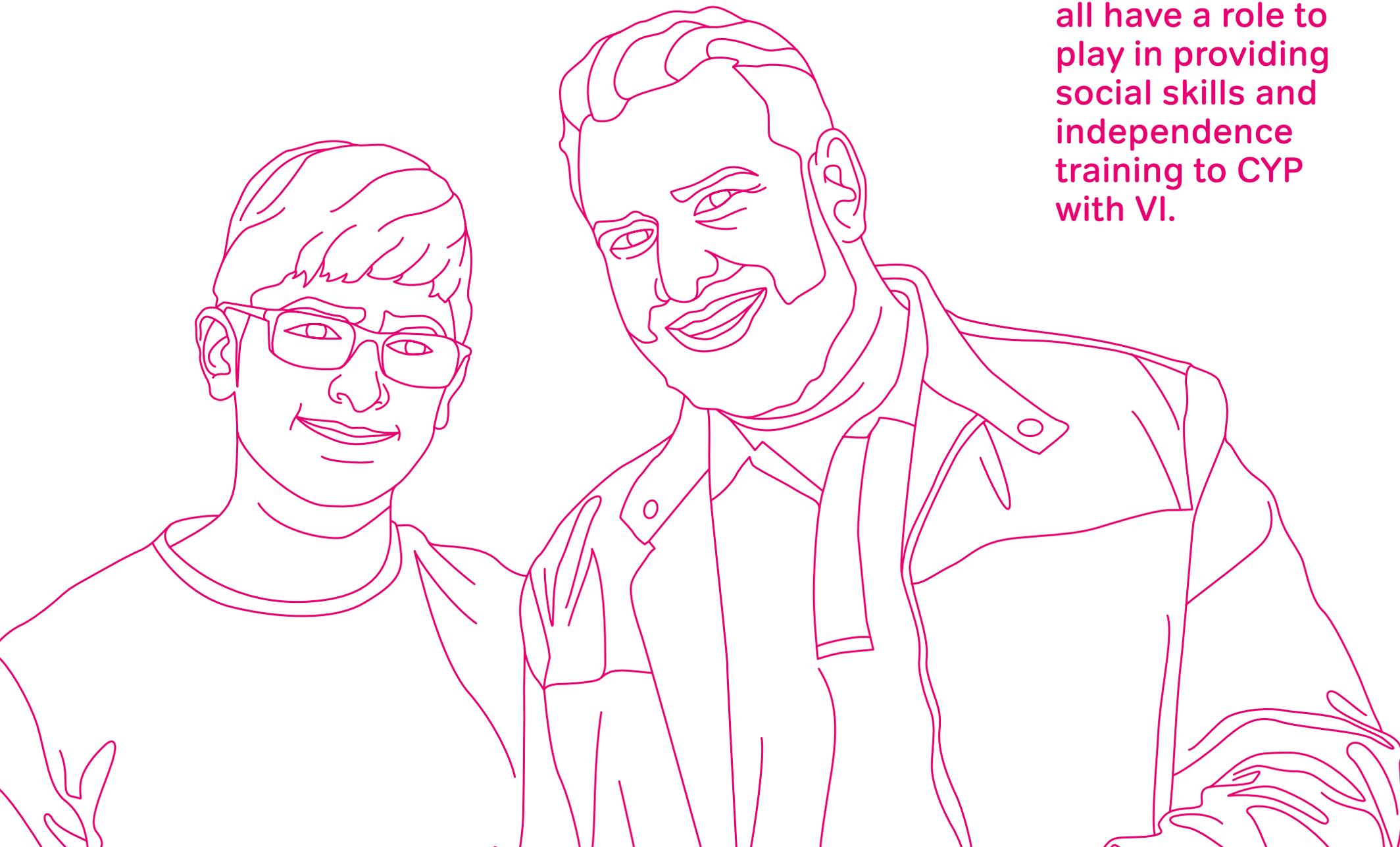
of CYP with VI have additional disabilities and/or chronic health problems, including many with multiple and complex needs



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.



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

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.

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