



Evidence-based review

Children and young people



supporting blind and partially sighted people

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Introduction

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.

Every year RNIB publishes “Sight loss UK”, which reviews the evidence we have about the lives of people living with sight loss.

This review looks in more detail at the experiences of children and young people who are blind or partially sighted. 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

There are an estimated 40,000 children and young people (CYP) aged up to 25 years with a vision impairment (VI) of sufficient severity to require specialist support in the UK. Of these approximately 25,000 are under 16 years old:

	0–25 years	0–16 years
England	34,000	21,400 (approx)
Scotland	3,235	1,970 (approx)
Wales	1,935	1,180 (approx)
Northern Ireland	1,260	810 (approx)

Source: ONS, 2012 [1]

In total 9,635 children and young people aged under 17 were registered as blind or partially sighted with social services in England at the end of March 2011 [2]. Registration is voluntary.

At least 20 per cent of young people with a vision impairment have additional disabilities and/or special educational needs and a further 30 per cent have very complex needs [3].

Causes and risks of visual impairment

Most blind and partially sighted children and young people are born with their vision impairment. Approximately two thirds of children with severe vision impairment and blindness had been diagnosed before their first birthday [4]. The single most common cause of vision impairment in children is cerebral vision impairment.

Children at most risk of severe vision impairment 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 [4].

There is a high prevalence of blindness and partial sight in children with learning disabilities (LD) [5].

Children and young people with LD and vision impairment are currently under-represented in official Department for Education (DfE) statistics. Evidence suggests that there are learners in special schools in the UK whose vision impairment has not been identified [6].

Children and young people with vision impairment are more likely than children without disabilities or special educational needs (SEN) to experience social and economic disadvantage [7].

Services and support

Health screening

The UK National Screening Committee (UK NSC) is responsible for reviewing screening policies every three years and making recommendations to ministers in the four UK countries about whether or not a screening programme for a certain condition should be set up. Screening procedures for vision are set out in the National Screening Committee Child Health Sub-Group Report on Vision Screening [8]:

- all newborn and 6-8 week old babies should undergo screening for vision defects as part of the routine review to exclude retinoblastoma, glaucoma and cataract since they are treatable and, respectively, life and sight threatening
- babies at a known higher risk of vision disorders should have a specialist neonatal ophthalmic examination, such as very low birth weight and pre-term babies or babies with a known hearing impairment or with other major disabilities
- a systematic population screening programme for visual impairment between 4 and 5 years of age should be offered by an orthoptic-led service; vision defects include amblyopia, refractive error and strabismus.

Education

Approximately two thirds of children who have a vision impairment (VI) are educated in mainstream schools, some of which are additionally resourced for learners with vision

impairment. Around one third attend special schools for pupils with learning or physical disabilities. Two per cent attend specialist schools designated for blind and partially sighted learners [3].

Young people with VI are well represented in Further Education (FE); in England in 2008/09 a total of 5,427 young people with VI, aged 16–18, were in FE or on Modern Apprenticeships [9].

There are only 12 specialist schools for blind and partially sighted learners in the UK (only one each in Scotland and Northern Ireland and none in Wales). These schools support fewer than 1000 learners, most of whom have complex needs. There are six specialist FE colleges for learners with VI, all in England.

There is considerable variation between local authorities (Education Boards in Northern Ireland) in levels of educational provision for learners who have a vision impairment. There is no standard threshold for receiving support from local authority vision impairment 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 [3] and to a lesser extent, in Wales [10].

The specialist practical support that children and young people with vision impairment typically require includes the following:

- 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 classroom resources and exams
- mobility training and independence skills, including daily living activities (habilitation)
- support for social and emotional development
- consistent funding for low vision assessments and prescription of aids
- support for parents in the care, development and learning of their child [11].

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-16 settings, via the local authority specialist education service for vision impairment, but provision varies [3].

Children and young people (CYP) may use non-sighted or sighted methods, or a combination of both, to access the school curriculum. Many use a combination of magnification, large print, electronic text and audio to access learning materials.

Around 5 per cent of CYP with VI in England and just over 3 per cent in Wales use braille as their sole or main literacy format [12]. Some young people with complex needs use alternative communication systems such as objects of reference.

Key professionals

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

- Specialist support is provided mainly by peripatetic qualified teachers of learners with vision impairment (QTVI) working for local authority VI services. QTVIs are required to hold a specialist qualification in vision impairment in addition to qualified teacher status.
- Teaching assistants (TAs) provide in-class and curriculum support. Some TAs are employed by local authority VI services but most are employed by individual schools. TAs are not required to have specialist training, although courses are available.
- A mobility teacher/habilitation worker should be available to teach children and young people with severe vision impairment how to move around more independently and how to do practical everyday tasks for themselves. National standards and training for habilitation workers with CYP were developed in 2011 as an outcome of the Mobility 21 Project funded by the Department for Children, Schools and Families in England. These quality standards are designed to make sure children and young people with vision impairment 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 [13].
- Health specialists such as ophthalmologists, orthoptists, and optometrists, specialise in the 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) 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, secondary 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 are also required to carry out accessibility planning to anticipate and improve their ability to meet the needs of disabled learners.

The Equality Act does not extend to Northern Ireland where the Disability Discrimination Act 1995 (DDA) still applies and the education protection under the DDA still stands.

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 children and young people include the following:

England

- 2001** SEN and Disability Act.
- 2011** The Education Act introduced direct payments for parents with regard to special educational provision and transport.
- 2012** The Children and Young People's Health Outcomes Forum report set new quality standards and clinical indicators.
- 2013** The Children and Families Bill currently going through Parliament seeks to develop a single statutory assessment process and a single education, health and care plan.

Scotland

- 2010** An update to the Education (Additional Support for Learning) Act extended the duty of care to non-educational providers such as Health, Social Work and Careers Scotland.
- 2012** Getting it Right for Every Child was updated to improve collaborative practice for multi-professional assessment and service delivery and to establish a "named person" to oversee the support provided to any child with additional support needs within a local authority.
- 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".

Wales

- 2011** Nurturing Children, Supporting Families – government childcare policy statement.
- 2012** Rights for Children and Young people – Welsh Government formally adopted the United Nations Convention on the Rights of the Child (UNCRC).
- 2013** Major education reforms are being piloted in Wales with Individual Development Plans proposed that incorporate education, health and social services' support. It is planned that these will replace new statements of special educational need. A Code of Practice, incorporating "pathway" documents, will set out best practice to support CYP with different disabilities.

Northern Ireland

- 2009** Every School a Good School: A policy for school improvement – a review of special educational needs provision.
- 2010** Healthy Child, Healthy Future – a framework for universal child health 2010: Healthy Futures 2010 –2015 looks at the contribution of health visitors and school nurses in Northern Ireland.
- 2013** The legislation and Code of Practice for SEN provision review is now being written.
- 2014** Education and Skills Authority (ESA) is set to replace five Education Boards.

United Kingdom

Although some policies differ across the UK, children and young people with vision impairment face many common issues and some common themes are emerging across the four countries:

- Developing alternatives to statements of special educational need, building on person-centred planning approaches.
- Bringing together education, health and social care provision through integrated planning and commissioning of services.
- Planning for children and young people 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 vision impairment

The population of children with vision impairment can be thought of as two distinct sub-populations: those with, and those without additional impairments/disorders [14]. The “patient journey” as well as a range of wellbeing and educational outcome measures are markedly different for children with a vision impairment as their sole disability, compared to those with vision impairment and additional disabilities or chronic health problems [14].

Diagnosis and early support

The period around diagnosis is critical for parents to understand their child's vision impairment and how it might affect how their child develops and learns and the support they might need to reach their potential [15].

Evidence shows that vision impairment is more likely to go undetected in children with additional disabilities, in children in some Asian ethnic groups and in children from deprived groups [14].

If babies with a vision impairment 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 [16]. Blind children, in particular, require high levels of specialist input to address crucial needs in their cognitive development, communication, social and independence skills [17].

Emotional wellbeing and social relationships

At age seven, children with vision impairment 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; or wet the bed at least once a week [7].

Parents and teachers of seven-year-old children with vision impairment were significantly more likely to say that the children were being bullied, than parents and teachers of children without vision impairment [7].

Young people with VI are regular users of information technology including mobile phones, and communicate regularly through social networking sites such as Facebook [18]. They are also interested in a wide range of leisure activities [19]. Children aged seven with vision impairment in the Millennium Cohort Survey were just as likely as fully sighted children to say they had "lots" of good friends [7]. 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 [18]. However just under half of the 50 participants in an Action for Blind People survey sample 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 [19].

Curriculum access and attainment

At all key stages the attainment of learners with vision impairment (as an SEN group) is lower than that of learners with no SEN, but higher than any other SEN group. We also know that at all ages, learners with VI as their only SEN do better in terms of their attainment and progress than learners with a VI plus an additional SEN [20]. The current evidence on educational attainment does not tell us the effect (if any) of severity of VI.

Although most children and young people with vision impairment are educated in mainstream schools, 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 [21] 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 [22].

Key longer term independence skills (including mobility and social skills) that fall beyond the academic curriculum may be neglected [23] and 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 [24].

Although teaching assistants (TAs) play an important role, they may also prevent social inclusion and have an adverse effect on educational attainment by acting as a barrier between the child and their classmates, and their class teacher [25]. RNIB has identified just under 1600 TAs supporting CYP with VI in 92 local authority VI services in England and Wales. The majority were employed directly by individual mainstream schools [12]. Evidence indicates that TAs can best support children with VI if they have an understanding of VI and how it affects the individual [23]. It is a matter of concern that several local authorities were unable to provide numbers of TAs employed directly by schools, as this suggests that these TAs may be working without the supervision of a QTVI from the local authority VI team.

Subject specific expertise has declined with the closure of specialist VI schools. This shortage can lead to difficulties when pupils are entered for national tests and exams, because of a mismatch between classroom practice and conventions used in exam papers [26].

Curriculum access issues are exacerbated by public sector cuts leading to reduced staff in local authority VI services and the threshold for access to support being raised as a consequence.

Transition to further study and employment

Ofsted, which relates to England only, has reported on the local variations in availability and quality of post-school provision for learners with specialist needs such as sensory impairment [27]. While most young people with vision impairment 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 [28]. Students with VI who had successfully completed college courses, emphasised that computer assistive technology and keyboarding skills were important and necessary skills to have before going to college [29].

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 parents 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 [30].

There is currently no comprehensive source of administrative or survey data that enables the pathways of young people with VI (with and without additional SEN) after they leave school to be tracked. So although analysis of the Labour Force Survey shows fewer 16 to 25 year olds "disabled due to a seeing difficulty" were employed compared to all young people in this age group, there is no reliable evidence about the numbers who are "not in employment, education or training", known as NEET [31].

For blind and partially sighted people, holding an educational qualification is a key enabler for obtaining employment [23]. 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. They include independent mobility skills, assistive technology skills and skills to communicate needs and associated adjustments to employers. 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 [19].

What the evidence tells us

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

- Experiences of health, education and social care are different for children with a vision impairment as their sole disability compared to those with additional disabilities. Policymakers 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 vision impairment should be divided into those with and those without additional disabilities.

Early diagnosis and support is crucial

- Unlike adults, most children with vision impairment 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 vision impairment and should be encouraged to use the *Developmental Journal for Babies and Children with Visual Impairment* [32]. The majority of these children need specialist support to minimise the developmental (and sometimes the emotional and psychological) impact of vision impairment. Therefore babies and children with vision impairment should be referred as soon as possible after identification to the local authority specialist vision impairment (VI) education advisory service for support from a qualified teacher of children with vision impairment (QTVI).
- At least 50 per cent of children and young people with vision impairment have additional disabilities and/or chronic health problems, including many with complex needs. For these children screening should be carried out by an ophthalmic specialist, as well as regular optometric screening for children in special schools. School entry vision screening at age 4-5 years is of particular importance in deprived areas.

Emotional wellbeing and social relationships are risk areas

- Children with vision impairment are at risk of poor outcomes across a range of emotional and social wellbeing indicators and the risks are even greater for children with vision impairment and another disability. Parents, mainstream educators and specialist support all have a role to play in providing social skills and independence training to children and young people with vision impairment.

Specialist support is essential for curriculum access and attainment

- Awareness-raising among mainstream teachers of the effects of vision impairment on learning is key to inclusive provision. All those supporting learners with vision impairment should have specialist training to ensure that they enable rather than prevent inclusion and independent learning. All children and young people with

vision impairment should be entitled to a full assessment by a QTVI, with education and habilitation provision in accordance with their assessed need.

- Children and young people with VI form a diverse but low incidence group. As a result, supporting professionals is often a question of identifying evidence of effective practice models and then addressing the challenge of how best these can be implemented in practice, given that most children are educated in non-VI settings.

Early preparation is needed for transition to further study and employment

- Evidence shows that if young people with vision impairment, with and without additional disabilities, are to be equipped with the skills required to succeed in post-school settings, a 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. Young people with additional needs making the transition from residential settings should also have the support of a dedicated transition worker.
- Support systems need to be put in place to prevent young people becoming socially isolated and NEET (not in education, employment or training) when they leave education.

References

Further information and links to all the references listed in this section can be found at our Knowledge and research hub: [rnib.org.uk/research](https://www.rnib.org.uk/research)

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About our evidence-based reviews

This evidence-based review is one of a series produced by RNIB researchers. Each review brings together key research about blind and partially sighted people of different age groups.

The series includes:

- **children and young people**
- **people of working age**
- **older people.**

In addition 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.

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

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