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ORIGINAL ARTICLE

Health, education, and social care provision after diagnosis of childhood visual disability

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Abstract

Aim: To investigate the health, education, and social care provision for children newly diagnosed with visual disability.

Method: This was a national prospective study, the British Childhood Visual Impairment and Blindness Study 2 (BCVIS2), ascertaining new diagnoses of visual impairment or severe visual impairment and blindness (SVIBL), or equivalent vision. Data collection was performed by managing clinicians up to 1-year follow-up, and included health and developmental needs, and health, education, and social care provision.

Results: BCVIS2 identified 784 children newly diagnosed with visual impairment/SVIBL (313 with visual impairment, 471 with SVIBL). Most children had associated systemic disorders (559 [71%], 167 [54%] with visual impairment, and 392 [84%] with SVIBL). Care from multidisciplinary teams was provided for 549 children (70%). Two-thirds (515) had not received an Education, Health, and Care Plan (EHCP). Fewer children with visual impairment had seen a specialist teacher (SVIBL 35%, visual impairment 28%, χ^2 $p < 0.001$), or had an EHCP (11% vs 7%, χ^2 $p < 0.01$).

Interpretation: Families need additional support from managing clinicians to access recommended complex interventions such as the use of multidisciplinary teams and educational support. This need is pressing, as the population of children with visual impairment/SVIBL is expected to grow in size and complexity.

Childhood visual impairment confers significant potential adversity on the individual, their family, and on wider society.[1,2] To address this at societal and individual levels, primary (preventing blinding disease from occurring), secondary (treatment of established disease to reduce negative impact), and tertiary prevention approaches are required.[3–5] Tertiary prevention approaches comprise interventions that mitigate the impact of established visual disability or associated disorders on the life of the child and the adult they become. These interventions may be simple, such as the provision of low vision aids, or more complex, such as the provision of parenting support, or the development of individualized 'packages' of multidisciplinary care for the additional physical, educational, psychological, and social developmental needs of the affected child.[6]

In recognition of the high burden of the numerous developmental and non-ophthalmic disorders that coexist in children with impaired vision, multidisciplinary assessment of children newly diagnosed with visual disability is advocated.[1,3,7] Almost two decades ago, the British Childhood Visual Impairment and Blindness Study (BCVIS; 2003) confirmed that in the UK most children newly diagnosed with severe visual impairment and blindness (SVIBL; vision worse than 1.0 logMAR [logarithm of the minimum angle of

This original article is commented on by Le Fanu on pages 729–730 of this issue.

Abbreviations: BCVIS, British Childhood Visual Impairment and Blindness Study; EHCP, Education, Health, and Care Plan; NHS, National Health Service; QTVI, qualified teacher of children and young people with vision impairment; SVIBL, severe visual impairment and blindness.

resolution], or 10-fold worse than normal levels, as defined by the World Health Organization's International Classification of Disease, 10th revision [ICD-10]) received early input from a range of professionals.[7] However, BCVIS also reported that only a third received care from a formal or dedicated multidisciplinary visual impairment team,[7] despite the importance of such teams in ensuring comprehensive assessment of the needs of the child and their family. Guidance on the necessity of the contribution of multidisciplinary teams to the care of children with visual impairment has since been incorporated into UK health recommendations.[8]

Children with moderate visual impairment (simply termed 'visual impairment', and defined internationally as vision between 0.48 and 1.0 logMAR in the better-seeing eye, i.e. 5- to 10-fold worse than normal vision) are also recognized as a vulnerable group, with a degree of visual disability indicative of the need for additional educational support.[8] There are evidence gaps in the understanding of the wider health care needs of, and use of, social and educational services by visually impaired children. Data sources necessary to address these gaps are lacking. For example, the information gathered from the process of certifying children as sight impaired or severely sight impaired (by which eligible individuals in the UK are offered inclusion in their local social care register to assist in accessing social care support and governmental financial assistance) does not include this information.[9] We hypothesized that, despite national recommendations, provision of support was not universal, and would vary by severity of visual impairment. We used data from a recent population-based prospective study, the British Childhood Visual Impairment and Blindness Study 2 (BCVIS2), to test this hypothesis.

What this paper adds

- One year after visual disability diagnosis, one in three children had not received the recommended care from a multidisciplinary team.
- Two-thirds had not yet received the recommended Education, Health, and Care Plan.
- There is an under-provision of recommended care, despite significant and complex need.

METHOD

BCVIS2 is a prospective, UK-wide, longitudinal cohort study of children newly diagnosed with visual impairment/SVIBL, which aims to determine the incidence, mode, or context of detection, determinants or risk factors, management, and short-term health and social outcomes of all-cause visual impairment and blindness in childhood. Detailed methods have been published elsewhere,[10] and are summarized here. Eligible children were those aged up to 18 years and newly diagnosed with impaired acuity to a level of 0.50 logMAR or worse in the better-seeing eye, or equivalent vision as assessed using standard qualitative metrics. Cases were ascertained using national active surveillance undertaken simultaneously but independently through the British Ophthalmological Surveillance Unit and the British Paediatric Surveillance Unit, the two networks of UK consultant ('attending') ophthalmologists and paediatricians respectively. Cases were ascertained in a 12-month period starting on 1st October 2015, with 784 confirmed cases of children newly diagnosed with visual impairment/SVIBL. Previously reported characteristics of the BCVIS2 cohort include a higher relative incidence of visual disability among UK children from ethnic minority backgrounds and those resident in areas of relative deprivation.[10]

Data collection occurred at diagnosis, with follow-up data collection no earlier than 1 year after diagnosis (to update diagnoses and confirm stability of visual impairment) completed into 2018 using study-specific standardized pro forma. These data comprised identifiers such as National Health Service (NHS) number and date of birth (to identify duplicate reports), sociodemographic characteristics, clinical information (classified using definitions in ICD-10), information on early management comprising diagnostic tests, treatments, the involvement of a qualified teacher of children and young people with vision impairment (QTVI; trained to provide direct support to infants, children, young people, and their families), the involvement of a multidisciplinary team, and provision of an Education, Health, and Care Plan (EHCP). The EHCP is a legally binding, nationally recommended document which sets out a child's or young person's (aged 0–25 years) personalized educational, social care, and broader health care needs to enable comprehensive provision by their local authority. The document is produced following assessment by the health professionals involved in the child's care. Data on sight impairment certification status were also collected from managing clinicians. In the UK, individuals can be certified as severely sight impaired (e.g. vision worse than 1.3 logMAR with a full visual field, or worse than 1.0 logMAR with visual field deficits), or having good central vision with severely limited field or sight impaired (vision 1.0–1.3 logMAR with a full visual field, or good central vision with visual field defect). All returned data were reviewed for completeness by a senior ophthalmologist (ALS). Reporting clinicians were contacted about missing data, or for clarification, as required.

Institutional review board/ethics committee approval was obtained through the UK Health Research Authority. The Health Research Authority Confidentiality Advisory Group granted the study exemption from Section 251 of the Data Protection Act, allowing use of data without individual consent on the grounds of public interest (reference 14/LO/1809). This research adhered to the tenets of the Declaration of Helsinki.

Analysis

The proportions of children receiving multidisciplinary clinical care and social and educational support during the first year following identification of their status as visually

impaired, severely visually impaired, or blind were calculated. Children were dichotomized by severity of visual disability (SVIBL vs visual impairment) and categorized by the age at diagnosis of visual impairment/SVIBL (<1 year, 1–4 years, ≥5 years), on the basis of milestones of infancy and school entry, to further explore patterns of care across these categories. Socioeconomic status was categorized using the Index of Multiple Deprivation, the standard UK area-based composite measure of deprivation derived from the postcode and ranked into quintiles. The disorders or condition(s) causing visual impairment/SVIBL were categorized using previously validated modified World Health Organization dual taxonomy,[7] which involves classification both by anatomical site(s) affected and by aetiological factors (i.e. timing of insult to the eye or visual system).

Data were analysed using STATA statistical software (version 14.2, StataCorp LLC, College Station, TX, USA). General descriptive statistics were calculated, with categorical data expressed as counts and percentages. A χ^2 test with Yates' correction was used for categorical variables. Any *p*-values less than 0.05 were considered to be statistically significant, and 95% confidence intervals are reported.

RESULTS

Of the 784 children identified by active surveillance through the BCVIS2 study, 313 were newly diagnosed with visual impairment and 471 newly diagnosed with SVIBL. The British Ophthalmological Surveillance Unit reported 664 cases, of which two were also reported independently by paediatricians. Cases were reported solely through the British Paediatric Surveillance Unit for 120 children.

Clinical characteristics of the cohort

Irrespective of severity of visual impairment, insults to the cerebral and visual pathway, the retina, and the optic nerve were the three most common groups of causative disorders for childhood visual disability (Table 1). Cerebral/visual pathway disorders were the most common diagnosis among those children newly noted to have SVIBL, affecting the majority (61%), with the remainder having visual disability due to 'peripheral visual disorders', namely ocular and/or optic nerve disorders. Retinal disorders were predominant among those with visual impairment. Complexity of disease at ocular level was noticeable across the spectrum of disability, with impairment being due to multiple affected anatomical sites in 439 out of 784 children, 56% (170 out of 313 [54.3%] children with visual impairment, 269 out of 471 [57.1%] of those with SVIBL).

Overall, most children exhibited complexity due to associated systemic disorders, affecting a total of 559 (71.9%) children across the full spectrum of visual disability, comprising 167 (53.7%) with visual impairment and 392 (83.9%) with SVIBL (χ^2 difference in proportions $p < 0.001$). Many children with visual impairment/SVIBL also had additional sensory or developmental impairment. These additional impairments were seen more commonly in the group with more severe visual impairment: deficits of mobility affected 204 (26%) overall, comprising 56 out of 313 (17.9%) children with visual impairment and 148 out of 471 (31.4%) with SVIBL (χ^2 test $p < 0.001$); learning disorders affected 176 children (23%) overall, comprising 54 out of 313 (17.3%) with visual impairment and 122 out of 471 (25.9%) with SVIBL ($p < 0.01$); and speech and language deficits affected 167 children (21%) overall, comprising 54 out of 313 (17.3%) with visual impairment and 113 out of 471 (24.0%) with SVI ($p < 0.05$). Hearing problems were equally common in both groups (105 [13%], comprising 35 out of 313 [11.1%] with visual impairment and 70 out of 471 [14.9%] with SVIBL).

Health professionals involved in care

The specialities and teams most involved in the care of children within the first year after diagnosis of visual impairment/SVIBL were specialized teachers (QTVIs) and multidisciplinary visual impairment teams (Figure 1). Overall, similar proportions of children with visual impairment and with SVIBL received care from a QTVI in the year after diagnosis. However, 165 children with SVIBL (35.0%) and 88 with visual impairment (28.1%) had not seen a QTVI in the first year after diagnosis of visual disability.

Composition of the visual impairment multidisciplinary teams did not vary by the severity of the child's visual impairment but did vary from hospital to hospital. In 64% of multidisciplinary teams, a paediatrician was part of the team (n = 44), ophthalmologists were team members in 47% (n = 30), orthoptists 41% (n = 26), mobility or rehabilitation specialists 14% (n = 9), speech and language therapists 14% (n = 9), clinical psychologists 11% (n = 7), and educational psychologists were present in 11% of teams (n = 7). Neurologists, physiotherapists, or occupational therapists, rehabilitation or mobility specialists, speech and language therapists, and dieticians were more likely to have been involved in the management of children with SVIBL than those with visual impairment (Figure 1). Of the 291 children with a genetic/hereditary condition, 60% (n = 175) were seen by a geneticist by 1-year follow-up, with no difference noted between children with visual impairment and those with SVIBL. Only 76 children (11%) with SVIBL were documented as receiving care from a psychologist or counsellor during the first year, although this figure was 20% for those children aged 16 to 18 years old at diagnosis of visual impairment/SVIBL. There were no differences in proportions of children in receipt of care from a multidisciplinary team, by residence in the most deprived (Index of Multiple Deprivation-based quintile) areas, or differences in receipt of input from a QTVI (94 out of 264 [36%] children resident in the most deprived areas had not been seen by a QTVI, vs 175 out of 508 [34%] resident in other areas, χ^2 p = 0.75).

TABLE 1 Comparison of the causes of visual impairment and severe visual impairment and blindness (SVIBL) by anatomical classification

	All children *n* = 784	Visual impairment *n* = 313	SVIBL *n* = 471	*p*
Cerebral/visual pathways	378 (48.2)	89 (28.4)	289 (61.4)	<0.001[a]
Hypoxic–ischaemic encephalopathy	118 (15)	34	84	
Structural abnormalities	113 (14)	28	85	
Non-accidental injury	9 (1)	2	7	
Neurodegenerative disorders	24 (3)	2	22	
Tumour	23 (3)	6	17	
Infection	21 (3)	3	18	
Metabolic	16 (2)	1	15	
Unknown disorder but evidence of cerebral/visual pathways	60 (8)	13	47	
Whole globe and anterior segment	95 (12.1)	12 (3.8)	83 (17.6)	<0.001
Microphthalmia/anophthalmia	40 (5)	1	39	
Anterior segment dysgenesis	24 (3)	5	19	
Multiple site coloboma	14 (2)	3	11	
Disorganized globe/buphthalmos/phthisis	17 (2)	3	14	
Glaucoma	42 (5.4)	12 (3.8)	30 (6.4)	0.17
Primary congenital	10	2	8	
Secondary	32	10	22	
Cornea	50 (6.4)	12 (3.8)	38 (8.1)	0.02
Opacity	29 (4)	4	25	
Dystrophy	2 (<1)	2	0	
Other corneal disorder	19 (2)	6	13	
Uvea	30 (3.8)	16 (5.1)	14(3.0)	0.13
Aniridia	17 (2)	10	7	
Uveitis	4 (<1)	2	2	
Other uvea disorder	9 (1)	4	5	
Lens	67 (8.6)	28 (8.9)	39 (8.3)	0.78
Cataract/aphakia	58 (7)	24	34	
Other	9 (1)	4	5	
Retina	286 (36.5)	143 (45.7)	143 (30.4)	<0.001
Retinopathy of prematurity	31 (4)	12	19	
Retinal and macular dystrophies	125 (16)	72	53	
Oculocutaneous albinism	60 (8)	42	18	
Retinitis[b]	4 (<1)	2	2	
Retinal detachment	36 (5)	7	29	
Retinoblastoma	3 (<1)	0	3	
Other	17 (2)	8	9	
Optic nerve	222 (28.3)	87 (27.8)	135 (28.7)	0.81
Hypoplasia	116 (15)	39	77	
Atrophy	89 (11)	31	58	
Neuritis/neuropathy	57 (8)	14	43	
Other optic nerve	17 (2)	3	14	
Other	14 (1.8)	8	6	

Data are *n* (%) unless otherwise stated. Non-exclusionary diagnoses, as children may have more than one disorder. Consequently, total exceeds 100%.

[a] χ^2 test for difference in proportions of visual impairment vs SVIBL.

[b] Retinitis can also be categorized within uveitis.

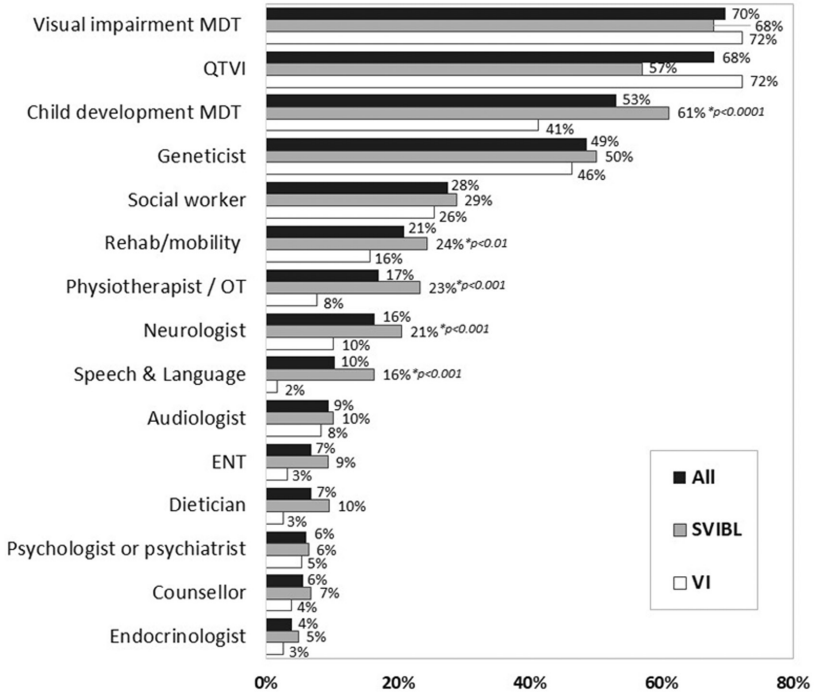

FIGURE 1 Care professionals involved in the management of children diagnosed with visual impairment (VI) and severe visual impairment or blindness (SVIBL). MDT, multidisciplinary team; QTVI, qualified teacher of children and young people with vision impairment; Rehab, rehabilitation; OT, occupational therapist; ENT, ear, nose, and throat specialist

TABLE 2 Completion status of Education, Health, and Care Plans (EHCPs)

	Children with visual impairment *n* = 313	Children with SVIBL *n* = 471	Total *n* = 784
EHCP already completed	21 (6.7)	52 (11.0)	73 (9.3)
EHCP in process	60 (19.2)	136 (28.9)	196 (25.0)
Uncertain/ unknown status of EHCP	232 (74.1)	283[a] (60.1)	515 (65.7)

Data are *n* (%). [a]Association between impairment severity (visual impairment vs severe visual impairment and blindness [SVIBL]) and absent EHCP production, $\chi^2 = 15.8$, $p < 0.001$.

Educational and social care

EHCPs had been recorded by 1-year follow-up for 9.3% of children with visual disability and were in process for a further 25% (Table 2). Of 402 children diagnosed with visual disability during infancy, plan production was not underway in 63.4%, with a similar absence of plan production seen in other age groups (aged 1–4 years, EHCPs absent in 132 out of 200 [66%]; aged 5–9 years, 71 out of 99 [71.7%]; aged ≥10 years, 57 out of 83 [68.7%]). Across all ages a higher proportion of children with visual impairment, when compared with children with SVIBL, had uncertain or unknown status for EHCP production (74% vs 60%, χ^2 $p < 0.001$, 95% confidence interval of difference in proportions 7.3–20.4%). The proportions of children without an EHCP did not vary by residence in socioeconomically deprived areas (no EHCP in 183 out of 264 [69%] children living in deprived areas vs 322 out of 508 [63%] in less deprived areas, χ^2 $p = 0.10$).

Certification of sight impairment or severe sight impairment, the non-mandatory process by which the managing hospital doctor notifies a child's local governmental authority of their visual problems, and of the urgency and degree of need for governmental support, was undertaken in 82% of children in the first year after diagnosis of visual disability (Table 3). As expected, owing to the non-coterminous definitions of visual impairment (an international taxonomy) and sight impairment (a national system), there was discordance of classification: a fifth of children with SVIBL were certified at the milder level of impairment (sight impairment) and a fifth of children with visual impairment were certified as severely sight impaired.

Reasons for non-certification before the end of the first year after notification of visual disability were reported for 68 of the 140 children (49%), and included reports from the managing paediatrician that the child was awaiting a follow-up consultation with a specialist ophthalmology team ahead of certification (*n* = 30), clinicians awaiting confirmation of the underlying diagnosis or presence of other developmental impairment (*n* = 26), clinicians awaiting confirmation of final visual acuity to determine whether to certify a child as severely sight impaired or sight impaired (*n* = 6), children being on palliative care (*n* = 4), and parental refusal of consent for certification (*n* = 2). Certification status did not vary by residence in areas of relative deprivation (220 out of 264 [83%] of

TABLE 3 Certification as sight impaired or severely sight impaired

	Children with visual impairment *n* = 313	Children with SVIBL *n* = 471	Total *n* = 784
Certified sight impaired	199 (63.6)	95 (20.2)	294 (37.5)
Certified as severely sight impaired	70 (22.3)	280 (59.5)	350 (44.6)
Not certified	44 (14)	96[a] (20.4)	140 (17.9)

Data are *n* (%). [a]Association between impairment severity (visual impairment vs severe visual impairment and blindness [SVIBL]) and absent certification, $\chi^2 = 4.7$, $p = 0.03$.

children resident in deprived areas were certified vs 414 out of 508 [82%] other children, χ^2 $p = 0.53$).

DISCUSSION

From this unique population-based cohort of children newly diagnosed visually impaired, severely visually impaired or blind (SVIBL), we report that children with visual impairment, when compared with those with SVIBL, are less likely to have non-ophthalmic disorders or impairments than children with SVIBL. However, there is still a significant health need for the population of children with visual impairment, with more than a third having additional sensory or developmental impairments, and most (just more than half) having associated systemic disorders. By 1 year after diagnosis of visual disability, most children with visual impairment/SVIBL have been seen by a multidisciplinary visual impairment team and/or an appropriately trained educational specialist (QTVI). However, more than a quarter of children had no documentation of contact with the appropriate educational specialist, and most had no documentation of completion of an EHCP. Children with visual impairment were less likely, compared with those with SVIBL, to have such a care plan produced. While appropriate support may be in place before agreement within an EHCP, an apparent lack of contact with an appropriate educational specialist in any proportion of children with visual impairment/SVIBL is of concern.

The strengths of this study lie in its population-based approach, resulting in a nationally representative cohort of children newly diagnosed with visual impairment/SVIBL, and data collection directly from managing clinicians. Conversely, this method of data collection may be limited by the assumption that the managing clinician has knowledge of, and access to, the broader care details of their patient. If this assumption is false, BCVIS2 is still able to report on the level of awareness of the managing clinician of the involvement of other teams, that awareness itself being an important marker of coordinated care.[11] The assumption that managing clinicians are aware of the care processes around their patients is likely to be correct, as the care provisions considered in BCVIS2 are triggered by the diagnosis of visual impairment/SVIBL by the clinician (referral to a QTVI and to a multidisciplinary team), or are directly implemented by the clinician (e.g. certification of sight impairment), or involves assessment by the clinician (i.e. contribution to development of the care plan).

Our study reports current care provision within a high-income country where health and social services are provided free at the point of access, which potentially limits the generalizability of study findings to other countries with different health and social service provision structures. This apparent limitation is important: the shortfall in care provision reported within BCVIS is likely to be replicated, and in some cases worse, in settings where services and resources are less available or less accessible. This is particularly important for middle-income countries which are still grappling with provision of neonatal care services for infants born preterm where rates of cerebral vision impairment and retinopathy of prematurity are likely to increase, the latter phenomenon now referred to as the 'third wave' of retinopathy of prematurity.[3–5,12] These children are likely to have improved survival rates, leading to a growing population of children with long-term complex health and care needs, especially within countries transitioning to higher economic strata. BCVIS2 is also potentially limited by the short follow-up period of the cohort data presented here, although the first year after diagnosis of visual disability is recognized as a crucial predictor for outcomes in later life.[3,10,11] This is particularly true for those 402 children (over half of the cohort) diagnosed in infancy. Nevertheless, this limitation highlights the need for longer-term national data on access to, and use of, health and educational services to sufficiently capture and evaluate access and use of services beyond the first year of diagnosis.

BCVIS2 helps to address key evidence gaps around the care of children newly diagnosed with visual disability, and these gaps bring an absence of comparative data against which to balance BCVIS2 findings. Studies of the broader health needs of children with visual disability typically involve populations of children educated at schools for the blind and/or with severe visual impairment or blindness (i.e. excluding those with moderate visual impairment).[12–16] The selection bias inherent in this approach means that such studies cannot comment on those children educated outside specialized schools, or on populations of children with less severe, but still life-changing, degrees of visual disability. Other studies have reported findings on the ocular clinical characteristics of children in the UK who are certified as severely sight or sight impaired.[9] As expected, BCVIS2 shows that these groups are not comparable to those diagnosed as having visual impairment/SVIBL, as the sight impairment categories are not coterminous with ICD-10 categories, or with any other internationally adopted taxonomy (e.g. the Systematized Nomenclature of Medicine). Additionally, the data returned through the certification system do not include the details of non-ophthalmic disorders or care.

The WHO–UNICEF–*Lancet* Commission for child health described the synergistic, cumulative 'immediate, long-term, and intergenerational' benefits of 'interventions to improve

health and wellbeing during childhood'.[17] Childhood visual impairment affects every sphere of health and wellbeing, and, for most, visual disability is present from birth, or occurs during infancy or early childhood, the foundational period for life outcomes.[18] Prompt identification of the health, education, habilitation, and psychosocial needs of children allows for the provision of those needs at hospital, community, and family levels, mitigating the negative impact of their disability on them, on the adult they become, and on wider society. This care is now also provided for children affected by 'moderately' poor vision, namely those with visual impairment, in recognition of the significant impact of this degree of disability.[1,6,8] Current UK recommendations are that complex interventions are provided after diagnosis of childhood visual impairment/SVIBL. These recommendations include the use of multidisciplinary teams and educational support to guide a child's learning about themselves and the world around them from infancy to adolescence, and provide information for all involved health and care professionals on the individual needs of vulnerable children.[7,19–22] The low proportion of children reported to have an EHCP for children in the BCVIS2 cohort, particularly those with visual impairment, is striking although the absence of a plan does not necessarily indicate that appropriate support is not in place. In the UK, although health care professionals are involved in the development of a plan for addressing educational and health needs, the assessment can be triggered by the approach of parents and carers to their local governmental educational authority. A common trigger for requesting this process can be commencement of a nursery placement. Our findings suggest that additional signposting for families of this important care pathway and of the benefits of early planning may be needed.

The BCVIS study reported that only a third of children newly diagnosed in 2000/2001 with SVIBL received care from a multidisciplinary visual impairment team. This led to guidelines around the integrated involvement of health, mobility, education, and child development professionals in the care of children newly diagnosed with visual disability;[6,7] it is reassuring to see from BCVIS2 that almost three-quarters of children diagnosed in 2015/2016 now receive health care from a multidisciplinary team, although the exact composition of the teams is unclear. However, one in four children in BCVIS2 did not receive educational support from a specialized teacher. This is of concern, because input from these specially trained teachers enables parental access to developmental support materials which have been shown to improve developmental outcomes and reduce parenting stress.[6,22,23] A recent UK Government review of the system of provision for children and young people with special educational needs/disabilities has suggested that delays in completion of EHCPs are due to increasing demand for support to be formalized through this process.[24] This increasing demand is due to a variety of reasons, which include longer survival of children with complex needs and increased recognition of the need for support for those with brain-based vision problems.[24] Parents should be suitably informed and supported to act as advocates for their child's needs, and this must be matched by provision of specialist services.[24] The UK requires increased numbers of, and effective use of, trained specialist educators to provide the necessary support for children with visual disability.[24] This shortfall in services will also apply to countries outside the UK, and will be more complex and compounded in countries where criteria for, and access to, health and education services differs between individual states or regions.

The global population of children with visual impairment/SVIBL is expected to grow further in number and complexity because of increased survival rates for children who have undergone neurodevelopmental insults during the 'first 1000 days'[2,25-27] as neurocritical care for vulnerable neonates continues to improve.[28,29] This growth is occurring at a time when the planning, commissioning, and delivery of preventive maternal health care will be challenged by post-pandemic recovery, workforce shortages, and sustainability concerns.[30] These challenges may also impair the delivery of interventions that seek to avert the negative impact of visual disability on later-life outcomes for affected children and families. It is also worth noting that, within BCVIS2, a third of children with a hereditary condition had not seen a geneticist during the first year after diagnosis of visual disability. The revolution in genomic medicine offers much hope to children with rare diseases, providing parents and managing clinicians with earlier diagnosis, a greater understanding of disease, and the prospect of personalized interventions.[31] Data on the complexity of needs for children with visual impairment/SVIBL, and on the potential gaps in addressing those needs, are key to understanding how best to provide health, education, and social care for this population, the vital step in ensuring access and equitable life outcomes for children with visual disability.

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CONFLICT OF INTEREST

The authors have stated that they had no interests that might be perceived as posing a conflict or bias.

DATA AVAILABILITY STATEMENT

The data that support the findings of this study are available from the corresponding author upon reasonable request.

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SUPPORTING INFORMATION

The following additional material may be found online:

Table S1: List of systemic diagnoses and disorders within the BCVIS2 cohort.

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