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Cerebral visual impairment and educational support in the United Kingdom

Understanding thresholds for providing support

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1 Cerebral Visual Impairment and Educational Support in the United Kingdom: Understanding
2 thresholds for providing support.

3

4 Introduction

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6 Cerebral Visual Impairment (CVI) is the most common cause of visual impairment in children in the
7 UK. The mainstay of management is providing strategies and environment adaptations to allow the
8 child to use their vision for learning and independence. It is therefore important to understand
9 educational access policies to facilitate timely and appropriate referral to qualified teachers for
10 learners with visual impairment (QTVI) by ophthalmologists.

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12 Methods

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14 QTVIs were recruited from VIEW (Visual Impairment England and Wales) and the Scottish Sensory
15 Centre (QTVI organisations) via email, newsletter and social media. Respondents were directed to
16 an online electronic questionnaire.

17

18 Results

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20 116 responses were received; this represents around 18% response rate. All services accepted
21 referrals for children with cerebral visual impairment (CVI). The majority of services (97%) did not
22 have a strict visual acuity threshold for children with CVI. There is an inconsistent approach in the
23 diagnosis of CVI across the UK, with some QTVI expressing concern that this had prevented children
24 with visual dysfunction from accessing help. QTVI indicated they would welcome more referrals for
25 Cerebral VI, at an earlier age, and that a formalised referral pathway would be beneficial.

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27

1 Conclusion

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3 Children with CVI are accepted for support by QTVI/sensory services regardless of visual acuity.

4 Services welcomed referrals for children undergoing assessment where CVI had yet to be confirmed.

5 However the formal diagnosis of CVI by an ophthalmologist as a pre-requisite to access services in

6 some areas emphasises the need to improve clinicians' confidence in the diagnosis of CVI.

7 Ophthalmologists are encouraged to engage with local QTVI/sensory teams to facilitate exchange of

8 information and appropriate and timely referral of children in need.

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Cerebral visual impairment (CVI) is the most common cause of visual impairment in children in the UK¹. Recent studies have shown that around 1:5 of children in special school² and one in 30 children in mainstream school have brain related visual problems³.

The mainstay of management of cerebral visual impairment is in developing strategies to enable children to use their vision more effectively, through adaptations to their environment and visual tasks they are required to perform in daily life. For children this encompasses adjustments to enable them to access education and maximise their academic potential. A UK study identified that parental and teacher understanding of the child's CVI and individual information on strategies to support the child were important to promote successful intervention⁴.

The recent publication of a Future Commission Report⁵ by the charity Guide Dogs highlighted how accessing services and support at the right time can be a gateway to increasing confidence, happiness and independence in children and young people with a vision impairment and can have a positive impact for parents, carers and families⁶.

The newly updated Royal College of Ophthalmologists Ophthalmic Services for Children Guidance⁷ states that 'children with a confirmed visual disability should have access to local QTVIs....Signposting families to these supportive services is important.' (p3) and 'Active regular communication to outside agencies such as visual impairment teachers is important' (p8). All children with visual dysfunction require referral to sensory support services and qualified teachers of learners with visual impairment (QTVI) by ophthalmologists. Whilst

1 some children will have coexisting ocular visual impairment (OVI), some of these children
2 will have normal visual acuity and a normal ocular examination.
3 It is therefore important for ophthalmologists to understand non-acuity based referral
4 criteria for children with CVI. This understanding is also reinforced by The National Sensory
5 Impairment Partnership (NatSIP) which defines vision impairment not through acuity but
6 through visual function. "From a functional standpoint, a child or young person can be
7 considered to have a vision impairment if this interferes with optimal development, learning
8 and achievements unless adaptations are made in the methods of presenting learning
9 experiences, the nature of the materials used and/or the learning environment"⁸

10

11 The aim of this study was to describe the current requirements and criteria used by
12 individual services for referral to QTVI/sensory services in the UK for children with a
13 diagnosis of cerebral visual impairment.

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16 Methods

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18 Participants were recruited via email, newsletter and social media posts to members of
19 VIEW (Visual Impairment England and Wales) and through the Scottish Sensory Centre,
20 Scotland, organisations for Qualified Teachers of the Visually Impaired (QTVI). Respondents
21 were directed to an online electronic questionnaire. Responses were anonymous and the
22 study was approved by the Biomedical, Natural, Physical and Health Sciences Research
23 Ethics Panel, University of Bradford. All responses received by the close date were included.

24

1 A copy of the questionnaire is shown in figure 1 encompassing the following areas

2 - visual acuity thresholds for referral (near, distance)

3 - requirement for sight impairment registration prior to referral

4 -requirement for formal diagnosis/consultant ophthalmologist involvement

5 -referral processes for cerebral visual impairment

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9 Results

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11 116 responses were received; 87 from England, 23 from Scotland, 4 from Wales and 1 from

12 Northern Ireland. There are approximately 650 QTVI in the UK: this represents around 18%

13 response rate.

14

15 **Visual acuity threshold for referrals for ocular or cerebral visual impairment**

16 22 (19%) respondents indicated their service adopted a distance visual acuity threshold for

17 referral into services, as shown in Figure 1.

18 Near acuity thresholds were described by 13 (11%) respondents, shown in Figure 2

19

20 However, all but 4 participants commented that in effect there were no acuity thresholds to

21 be met for a referral to QTVI to be made. Rather, a more holistic needs-based approach was

22 taken, in relation to visual field, nystagmus, cerebral visual impairment, and night

23 blindness/photophobia.

24

1 **Referrals for Cerebral Visual Impairment**

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3 All services accepted referrals for children with cerebral visual impairment from
4 ophthalmology teams. 74/96 (77%) respondents offering additional information indicated
5 there were no specific criteria or thresholds to be met. 24 respondents (21%) commented
6 on the importance of a diagnosis of “cerebral visual impairment” being specifically
7 mentioned in the referral for them to begin the assessment process. Six services were able
8 to accept a child with suspected CVI and one respondent stated their team were involved in
9 the diagnosis and assessment process in conjunction with the hospital eye team.

10

11 Two respondents required combined ocular and cerebral visual impairment with acuity of
12 6/12 and 6/19 being set by their local schools as a threshold for funding. One practitioner
13 explained how, for children with normal acuity, it was important for clinicians to specify in
14 the referral that visual impairment was a barrier for the child to access learning.

15

16 Free text comments revealed two main themes:

17 1) Variation in approach from ophthalmologists around diagnosis and referral to
18 refer to QTVI – either

19 A. Cerebral Visual Impairment was underdiagnosed and/or under-referred
20 by hospital specialists (16 respondents) or

21 B. There had been a recent increase in workload due to Cerebral Visual
22 Impairment referrals (14 respondents)

23

1 2)Referrals often lacked detail regarding the areas of the child’s visual dysfunction

2 (13 respondents)

3

4 Under diagnosis of CVI was perceived by one respondent to be more often seen in children
5 with complex needs. An equal number of respondents commented positively and negatively
6 about local attitudes to CVI diagnosis. Some reported that their local eye service were
7 closely involved with QTVI and made a lot of CVI referrals, where as others lamented a lack
8 of interest from local ophthalmologists who are more reluctant to make the diagnosis, and
9 symptomatic children are sent away being told there is nothing wrong with their vision.

10

11 On a more positive note, three respondents reported recent training they had received in
12 CVI and that a structured approach to referrals, assessments and provision of support had
13 been developed.

14

15 **Sight Impairment Registration** (England, Wales, and Northern Ireland only)

16 Only two respondents indicated that sight impairment registration was a pre-requisite of
17 being able to accept a referral. One respondent stated this was a result of funding being
18 delegated to schools and that each set their own threshold for ‘buying in’ services. One
19 service indicated that funding for habilitation services may be affected by sight impairment
20 registration.

21

22

23 This study has certain limitations: we cannot be certain that the respondents represent the
24 whole of the UK, nor that reporting bias may be present for those participants who have an

1 interest in CVI. To preserve anonymity, we were unable to collect data on the participants
2 education authority. We cannot be certain that multiple responses were not received for
3 the same education authority; however, it could be supposed that QTVI may have decided
4 amongst the team which member would respond to the study recruitment email. The
5 strength of the study is in the diversity of views expressed, representing the spectrum of
6 experiences which parents and children may encounter and making a case for reducing
7 inequalities in access.

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10 Conclusion

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12 The James Lind Alliance Sight Loss and Vision Priority list⁹ rated cerebral visual impairment
13 identification, prevention and treatment as its top research priority in childhood onset
14 disorders. Studies into the temporal trends in visual impairment in children in the UK state
15 that ‘tackling cerebral visual impairment is now the biggest challenge and biggest
16 opportunity for reducing the burden of childhood blindness’¹⁰

17

18 The results of our study show wide ranging variation in practice with regard to QTVI
19 referrals and support for children diagnosed with Cerebral Visual Impairment. It is clear that
20 no national visual acuity threshold criteria exist for referral into sensory services/QTVI and
21 that local areas develop their own policies. Future studies would benefit from a targeted
22 approach to individual education authorities to maximise response rate and coverage across
23 all regions of the UK. This would also provide a more reliable denominator from which to
24 draw conclusions. Developing standardised criteria for services is complicated; however the

1 call for a universal process by the study participants is echoed in a recent Creating The
2 Future Commission from a national sight loss charity⁵.

3

4 It is noteworthy how important it is for the referring ophthalmologist to state cerebral visual
5 impairment on a letter to QTVI services. Ophthalmologists may be unaware that nearly a
6 quarter of services were unable to offer support in the absence of a formal diagnosis by an
7 ophthalmologist. It is also evident that providing adequate information regarding the nature
8 of the child's visual impairment, beyond a simple acuity measurement, is valued by QTVI for
9 them to begin the assessment process. A Core Outcome Set for children with CVI was
10 recently published to establish baseline function and demonstrate progress, and this may be
11 a useful starting point¹¹.

12

13 Even though the responsibility for Education has been devolved to the four nations of the
14 UK it is clear however that across the UK QTVI consider any child in whom vision may be a
15 barrier to learning warrants referral into education sensory services. Communicating this
16 message clearly to ophthalmologists is important to have a lasting impact on the learning
17 outcomes of the growing population of children with CVI.

18

19 The study has revealed barriers which children with CVI may experience in fulfilling their
20 potential, and the role that eye health professionals play in improving this.

21 Ophthalmologists are unlikely to have an in-depth knowledge of local resources and
22 requirements within education and habilitation; it is therefore vital that they understand
23 how and when to refer a child into sensory services to enable them to access support.

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