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## **Towards removing barriers in the evaluation, diagnosis, and care of individuals with cerebral visual impairments**

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## **HIGHLIGHTS**

This paper provides guidance for the following policy initiatives regarding cerebral visual impairment (CVI):

1. Implementation of an inclusive and internationally accepted definition of CVI that encompasses the spectrum of potential visual dysfunctions and impairments that may be present.
2. Expansion of the definition of visual impairment to include CVI within the umbrella of diagnostic criteria at the local, regional, national, and international levels to ensure accurate diagnosis and increase access to services for individuals with CVI
3. Systematic and routine screening for those at risk for CVI to promote identification and intervention as early as possible to ameliorate potential short- and long-term effects of CVI.
4. Development of validated, reliable, and sensitive assessment tools and intervention approaches that encompass the full spectrum of sequelae for CVI.
5. Inclusion of CVI-related content training programs for medical, education, and rehabilitation training professionals.
6. Increase the availability of multidisciplinary CVI teams locally and regionally that are composed of informed professionals who work collaboratively in direct assessment and intervention programs. Populations served, methods used and outcomes achieved can be incorporated into comprehensive registries at the local, regional, national, or international levels to assist in the design of research studies and program implementation.

## **ABSTRACT**

Cerebral visual impairment (CVI) is a leading cause of pediatric visual impairment worldwide. Despite the ramifications on multiple developmental domains and quality of life factors, substantial barriers remain for evaluation, diagnosis, treatment, and education of this growing population of children and adults. At the root is a lack of consensus on the definition and diagnostic criteria of CVI and a narrow ocular/acuity-based classification of visual impairment. Both issues need to be urgently addressed to make strides toward removing current barriers. These challenges highlight the need for policy change at multiple levels to help ensure that individuals with CVI will have access to appropriate (re)habilitation and education services regardless of their acuity or visual function. Suggested solutions include the implementation of a globally accepted definition of CVI and increased multidisciplinary training programs. These will support international efforts to develop and implement quantitative interdisciplinary assessment methods, identify meaningful and effective intervention approaches, and monitor long-term outcomes for those with CVI. Additionally, sensitive and specific markers can be identified for differentiating CVI from other related developmental conditions, such as autism spectrum disorder and developmental coordination disorder. Ultimately, these proposed changes will lead toward improved quality of life for individuals with CVI and their caregivers.

### **Introduction of CVI and the main challenges that the article is addressing**

Cerebral visual impairment (CVI) is reportedly a leading cause of pediatric visual impairment worldwide (Chong et al., 2019; Hatton et al., 2007; Pehere et al., 2018). Despite the ramifications on multiple developmental domains and quality of life factors, substantial barriers remain for evaluation, diagnosis, treatment, and education of this growing population of children and adults. At the root are four main factors: 1) lack of consensus on the definition and diagnostic criteria of CVI; 2) narrow ocular/acuity-based classification of visual impairment across medical, education, and governing bodies; 3) a need for valid and reliable assessments; and 4) a need for validated, effective, and evidence-based interventions.

These four issues need to be urgently addressed to make strides toward removing current barriers in the diagnosis, assessment, care, and education of individuals with CVI.

As outlined below, without internationally accepted naming and diagnostic criteria for this condition, the roadblocks limiting improvements in the care of children, youths, and adults with CVI will remain, and those individuals who need access to services will likely continue to struggle to obtain them. This has widespread implications that extend from the medical and scientific communities to educators, interventionists, and (re)habilitation professionals.

### **Four Main Driving Forces Behind the Issues**

#### **Main Issue #1: Lack of consensus on the definition and diagnostic criteria for CVI in both the medical and education contexts**

Currently, one of the current main issues that must be resolved is the lack of consensus on the naming, definition, and diagnostic criteria for CVI.

The issue of whether the “C” in CVI stands for “cortical” or “cerebral” has been debated in the literature for many years (Colenbrander, 2011; Dutton, 2011b; Frebel, 2006; Jan, 2011b, 2011a; Lueck & Goodrich, 2011), with supporters on both sides of the aisle. Much of the debate is rooted in history. As outlined by Kran and colleagues (Kran et al., 2019), the ICD code describing CVI is one for “cortical blindness”, which according to ICD-10 refers to a “total loss of vision in all or part of the visual field due to bilateral occipital lobe damage or dysfunction” (<https://www.icd10data.com/ICD10CM/Codes/H00-H59/H46-H47/H47-/H47.61>, accessed 04/20/2023). The term “cortical blindness” was initially used to describe the visual impairment experienced by soldiers from World War I who sustained injuries to the occipital lobe and experienced a loss of vision as a result. Since that time, it has been widely recognized that the term “cortical blindness” does not account for the full extent of potential visual impairments and dysfunctions that are secondary to brain injury, damage, surgery, or malformation, particularly as many of these individuals present with normal or near-normal visual acuity and unrestricted visual fields (Chandna et al., 2017, 2021; Ghahghaei et al., 2021). In light of this, some began

using the term “cortical visual impairment”, while others began using the term “cerebral visual impairment” as it is more encompassing (i.e., Colenbrander, 2011; Dutton, 2020). Unfortunately, *the current lack of consensus as to what the “C” stands for in CVI* has led to a schism and disagreements on the diagnosis and management of the condition, ultimately impacting those with or at risk for CVI at multiple levels, from screening, assessment, and diagnosis to (re)habilitation, education, and intervention services received.

In addition, a continuing issue related to diagnosis for individuals who have CVI is the *lack of a unified definition that encompasses the full scope of manifestations associated with CVI*. A definition of CVI that is clear and consistent will improve child-find activities and broaden access to quality medical, educational, and related services. It will aid in securing more definitive diagnoses and will likely also serve as a teaching tool, since it may be the first avenue by which professionals, caregivers, or stakeholders learn about CVI. It is also important that any definition of CVI used in an educational context considers the Office of Special Education Programs’ (OSEP) needs-based guidance and incorporates language that states how CVI affects educational performance (including academic, social, vocational, and competencies over time) and conveys that without assessment and intervention, general education for learners with CVI would be insufficient (McDowell, 2021).

Furthermore, there is currently *no consensus on criteria and tools for the assessment, screening, and diagnosis of CVI*. Indeed, CVI is often a diagnosis based on exclusion - when the visual impairment is more severe than would be anticipated due to abnormalities in the anterior visual pathway (Chorna et al., 2017; Deramore Denver et al., 2016; Froude et al., 2016; McConnell et al., 2021; Philip et al., 2022). A diagnosis of CVI can be particularly challenging to obtain when there is no known risk factor (i.e., preterm birth, brain injury or malformation, genetic disorder, etc.), neuroimaging is typical, and/or basic visual functions such as acuity and visual fields are normal (Chandna et al., 2021). This is especially the case when medical professionals are not fully trained in the spectrum of ways in which CVI can manifest and impact function across developmental domains (Maitreya et al., 2018).

Because of the complex amalgam of potential CVI manifestations, a child at risk for or suspected of CVI should be evaluated by an experienced multi-disciplinary team (Boonstra et al., 2022; Ortibus et al., 2019). However, it can be challenging to access trained medical and educational professionals who fully understand the complex manifestations of this condition (Sakki et al., 2017). Critically, families with limited access to resources and are experts well-versed in CVI (either due to geographic location or income below the poverty threshold) are disproportionately affected (Almagati & Kran, 2021; Schwartz et al., 2021).

## **Main Issue # 2: Narrow definition of visual impairment at local, regional, national, and international levels.**

A second main issue is that the definition of “visual impairment” at the local, regional, national, and international levels in most cases is *based on visual acuity and visual fields, excluding visual perceptual impairments*.

From an education standpoint, without a definitive medical diagnosis of visual impairment, many students may have been denied approval for an initial educational evaluation for special education services that address CVI-related behavioral consequences. For example, in the United Kingdom, guidance from the Royal College of Ophthalmology Ophthalmic Services for Children states that: “children with a confirmed visual disability should have access to a local Qualified Teacher of Learners with Visual Impairment (QTVI).” However, it is unclear what is classified as a “confirmed visual disability”. This of course would depend in part on how “vision” was evaluated and what the thresholds for impairment are. In essence, this creates confusion over who qualifies for services. Pilling and Ravenscroft (2022) investigated whether a confirmed diagnosis was affecting access to the education services provided by the QTVI. From 116 responses from all parts of the United Kingdom, 21% of services noted the importance of having a formal diagnosis of CVI to gain access to support, whereas 77% responded that a needs-based approach was being utilized for children to gain access to the (QTVI) service.

In the US, medical and functional definitions of visual impairment may differ for entitlement to education services. Thus, some students with CVI may still qualify for education services based on their level of visual impairment even though their visual acuity and visual fields may surpass the threshold to meet the current US definition of visual impairment from a medical perspective (Goodrich, 2015; Kran et al., 2019; Ryder, 2017). The importance of this distinction has not been widely accepted worldwide. Consequently, **a needs-based**

***approach has not been universally adopted*** throughout the world (St Clair Tracy & Ravenscroft, personal communication, April 13, 2023), with many anecdotal reports pointing to a formal visual impairment diagnosis as the gatekeeper to services. Hence, students who have CVI but do not meet the medical definition of visual impairment based on traditional definitions (i.e., acuity reduction and/or visual field restriction) may be denied services. This outright denial of specialized services for students with CVI based on unclear and outmoded definitions is exclusionary.

Together, these first two main issues (i.e., a lack of consensus on the definition and diagnostic criteria for CVI along with a narrow definition of visual impairment/legal blindness) make it difficult to determine how many children, in fact, have CVI. In turn, this impacts access to appropriate education services, as well as resource allocation and training for educators and interventionists. A recent study estimated that as many as 3.4% of children in mainstream schools in the UK may have CVI-related behaviors, with upwards of 50% of children in special schools. Note that fewer than one in five of these had reduced visual acuity (Williams et al., 2021). Within the US, between 0.8 and 6.8% of children under the age of 18 years are blind or visually impaired (Center for Disease Control and Prevention, retrieved April 17, 2023 and American Community Survey data in 2019); however, the proportion of these who present with CVI-related vision problems (as opposed to reduced acuity and restricted fields) has not been fully ascertained. Statistics from 2022 for young children birth through 36 months from 19 states in the American Printing House for the Blind's (APH) national registry, called 'Babies Count', identify 32.3% (n = 244 of 755 total) of the infants and toddlers in the registry as having CVI or delayed visual maturation (Snyder et al., 2022). But if we extrapolate loosely from the UK survey figure of 3.4% and based upon a reported total US school enrollment of 49.5 million in Fall, 2021 (Institute of Education Sciences, 2023), as many as 1.68 million students of all ages could be estimated to have CVI-related vision problems in the US. Again, these figures emphasize the need for real and accurate data.

Each state is responsible for defining disability categories based on federal definitions; however, differences in the definition of visual impairment exist between states, with some states having definitions narrower than the definition in the IDEA and not inclusive of brain-based visual impairments. This ultimately may impact access to services for individuals and children with visual impairment.

In 2017, OSEP issued a non-binding guidance memorandum that appears to support a broader interpretation of visual impairment for access to special education services than definitions have been previously used in many states. The agency's memo indicated that qualification for education services for visual impairment in the US is related to the effect of visual impairment on a child's educational performance and not on the typical measures of visual acuity and/or visual field (Ryder, 2017). This memo has brought these issues to the attention of states who can now reconsider their visual impairment definition to reflect the guidance memorandum.

### **Main Issue # 3: Need for validated, reliable, quantitative, sensitive, & specific CVI assessments across the spectrum of potential manifestations**

Standardized guidelines for medical and education practitioners for referral, diagnosis, and identification of students who have CVI have not been formalized (Dutton, 2013). This leads to diverse approaches that may lead to confusion among practitioners and educators, undue concern for families, and ultimately, inexpedient and inappropriate services to the students (McConnell et al., 2021; McDowell, 2021; Oliver et al., 2023). Below we outline considerations surrounding the medical and educational evaluation of children with CVI, including potential implications for access to services.

The complex manifestations of CVI may be contextual, nuanced, and challenging to observe and quantify. Because of this, wherever possible the assessments should be multi-pronged, derived from multiple sources, and include quantitative assessments of visual function and functional vision, along with caregiver and/or patient interviews through a structured history-taking protocol (Dutton, 2011a; Dutton et al., 2010; Philip et al., 2016; Swaminathan et al., 2019). They should also include direct observation of behavior, formal and informal qualitative assessment of visual functions and functional vision, evaluation of skills across developmental and educational domains in school, home, and community settings, analysis of the physical environment and instructional material, and diagnostic teaching (i.e., intervention methods and results are carefully monitored) (Lueck et al., 2019; Philip et al., 2016). Partnership with individuals with CVI and their families helps to

establish CVI manifestations at the outset, as they can relate first-hand information on functional outcomes. There are many useful questionnaires that can expedite this and may be helpful in identifying potential CVI in children (Hellgren et al., 2020), as parents have been shown to be very effective in their responses to these tools (Garcia-Ormaechea et al., 2014; Pueyo et al., 2014). Higher order visual perceptual functions associated with the dorsal and ventral networks should also be quantitatively investigated. Eye tracking technology may be useful in cases where conventional neuropsychological methods are challenging due to comorbid cognitive and/or communication difficulties (Ben Itzhak et al., 2023; Bennett et al., 2018; Good et al., 1994; Huo et al., 1999; Kooiker et al., 2016; Mayer et al., 2020; Mooney et al., 2021, 2021; Tanke et al., 2021). Additionally, screening for infants and toddlers at risk for CVI needs to be implemented as early as possible with follow-up and monitoring over time. Screening tools need to be reviewed for their specific applications and relevance to individuals with CVI and disseminated to the field. (e.g., Cavézian et al., 2010; Chandwani et al., 2022; Chorna et al., 2017; Garcia-Ormaechea et al., 2014; Kim et al., 2022; Pueyo et al., 2014). Moreover, as individuals with CVI may have co-occurring ocular and cerebral causes of visual impairment (Ben Itzhak et al., 2019; Fazzi et al., 2007), evaluations ought to carefully consider the ramifications of each source of dysfunction. Thus, implementing a multidisciplinary assessment and intervention team, well-versed in CVI, and with open channels of communication enables the impact of CVI on daily functional skills to be more fully captured and to better implement interventions that may improve performance across the range of effects of the condition (Boonstra et al., 2022; McConnell et al., 2021; Ortibus et al., 2019). Currently, this may be challenging as resources to achieve this may be limited and every member of the team may not yet fully understand the diagnostic criteria, evaluation approaches, or consequences of CVI (e.g., Harpster et al., 2022; Mazel et al., 2019; Salavati et al., 2017). Actively seeking out various members with pertinent areas of expertise will help ensure that the assessment data related to the learner's use of vision is contextualized within their other sensory systems and educational needs (Lueck & Dutton, 2015). Regardless of which assessment is implemented, professionals need to consider their own biases and the limitations of the methodologies used as they attempt to make subjective evaluations of their patient's or learner's visual use.

One of the challenges associated with evaluating and diagnosing a child with CVI is that some of the behaviors associated with CVI may mirror behaviors noted with other medical conditions. Behaviors noted can be due to different underlying causes and can require different interventions. Vision, especially where visual acuity is typical, is frequently not considered the cause of developmental or behavioral difficulties, despite a growing body of evidence precluding typical visual acuity as a necessary component of CVI. (Chandna et al., 2021). Misdiagnoses or diagnoses where behavioral sequelae overlap can be confounding and can lead to intervention plans that may not lead to optimal improvement in performance. (e.g., Chokron et al., 2020; Chokron & Dutton, 2016; Fazzi et al., 2019; Kovarski et al., 2021; Wilton et al., 2021). Furthermore, as children enter school programs and progress through school with ever-increasing performance demands, subtler signs of CVI that may not have been detected at early ages can surface that require diagnostic and educational evaluation (Sweet & Franzsen, 2022). As a result, some students with CVI often remain undiagnosed or diagnosed later than expected (Williams et al., 2021), highlighting the need for a timely and thorough multidisciplinary evaluation for CVI in those at increased risk.

Even with a confirmed CVI diagnosis, there are still many hurdles that must be negotiated by students and families to obtain support services. To qualify for education services according to the Individuals with Disabilities Act (IDEA), a student must receive a comprehensive assessment that leads to an Individualized Education Program (IEP) or, for children under three years, an Individualized Family Service Plan (IFSP). Obtaining an accurate and complete assessment for students with CVI can be challenging for several reasons which are outlined below.

Access to appropriate educational services for children with disabilities is established under Part B of the IDEA and through the conduct of an evaluation. The law mandates that evaluations use multiple measures to determine if the child has a disability and use technically sound instruments (20 U.S.C. § 1414 (2)(C), 34 CFR §§300.304-300.311) that are valid and reliable for the purpose used (20 U.S.C. § 1414 (3)(A)(iii)). Although recent advances in CVI knowledge and practice have led to new tools and assessment procedures, in comparison to other disability categories under the IDEA, technically sound instruments used for CVI evaluation are limited (Kran et al., 2019) and educators have access to few CVI-specific tools. While reliance

on multiple methods of assessment paired with best-practices for visual impairment and blindness in general is considered optimal (Lueck et al., 2019), validity and reliability testing of available assessment protocols is minimal and is needed to prove with confidence that (a) tests measure what they purport to measure, and (b) assessments used to track and monitor children with CVI are based on experimental research designs that clearly illuminate the effect of one variable on another. In addition, common validated assessment tools targeting more general populations may not be appropriate for children with CVI who may not be included in population samples.

One must also keep in mind that an assessment approach that only considers the use of vision will not suffice in providing the kind of quality data that will lead to improved and comprehensive educational interventions and outcomes. Assessment procedures and tools must consider the use of other sensory systems and how the learner recognizes, perceives, decodes, and comprehends multisensory information in a variety of contexts using a variety of sensory systems (Mazel et al., 2020). The visual system does not function in isolation of other sensory systems (Lueck & Dutton, 2015), nor does it function in isolation of the learner's environment where sensory information is always multimodal and dynamic (Merabet & Ravenscroft, 2023).

Likewise, in the case of coexisting medical conditions, the more immediately evidenced conditions are often the main foci of intervention plans. For example, visual impairments in children who have cerebral palsy and other neurological conditions are often treated as secondary to their motor impairments in terms of intervention and habilitation strategies (Oliver et al., 2023). With the breadth and depth of the effects of CVI not understood and overshadowed by other issues, intervention programs may overlook critical areas of concern for individuals who have CVI (Chokron et al., 2021; Chokron & Dutton, 2016, 2022; Wilton et al., 2021).

It is now recognized that CVI affects more than vision and vision-related performance. More widespread effects stemming from CVI can be experienced early in development or after many years have passed. While students and their families are grappling to understand and ameliorate the potentially wide-range of CVI outcomes, professionals may be unaware of these multidimensional effects. Without early identification and continued follow-up, results from CVI anomalies can cascade and become ingrained into other functional domains such as language, gross and fine motor, socialization, and cognition (Lueck et al., 2021). These more complex and confounding consequences may not be identified and addressed through available educational assessments and can lead to additional functional and learning needs down the line for students who have CVI (Lueck et al., 2021; Morelli et al., 2022).

In essence, without validated and reliable assessment tools specific for CVI, children may be denied appropriate education services. On the medical side, without specific tools, it can be challenging to diagnose CVI in many individuals, including those with complex medical needs and comorbidities, as well as those with good visual acuity.

#### **Main Issue # 4: Need for validated, reliable, quantitative, sensitive, & specific CVI interventions across the spectrum of potential manifestations**

Similarly, there is a need for effective intervention approaches that have undergone rigorous and robust testing to ensure that any potential change in outcome is indeed due to the intervention applied, rather than other factors.

Because intervention is a time-consuming and costly, yet necessary, process, it is best practice to ensure that implementation of interventions is systematic, research-based, explicit, and tailored to meet the unique needs of the individual with CVI (Delay et al., 2022; Office of Special Education Programs, U.S. Department of Education, 2018; Weden et al., 2022). Notably, no single approach or method will apply to all individuals with CVI (Dale et al., 2022; Lueck et al., 2021; Mazel et al., 2020). Therefore, there is the need to establish a range of evidence-based intervention approaches that are tied to evidence-based assessments. Pilot studies and single case studies reporting successful outcomes are available (e.g., Lueck et al., 1999; Pilling & Little, 2020) as well as "promising practices" based on valued input from interventionists and caregivers (Tibaud, 2023). Presently, research evaluating the degree of implementation and effectiveness of a variety of intervention approaches is minimal (Delay et al., 2022). In addition, given that the evidence-base for interventions is minimal, many intervention approaches may miss their targets for particular children with CVI since they do not differentiate the causes of the child's visual, visual perceptual, and other difficulties. For example, inaccurate

visual guidance of reach can be caused by many different aspects of cerebral visual impairment, not just optic ataxia. Different root-causes require distinctive support strategies. Since interventions need to be individualized and tied to the unique needs of each person with CVI, the development of general intervention guidelines can be restrictive and can be misleading when the underlying causes are not clearly understood. Moreover, since CVI affects the 'whole child' and not just vision and visual perception, research evaluating intervention methods must take into account all interaction effects of co-occurring non-visual interventions that may impact a student's overall function (Chokron & Dutton, 2022; Lueck et al., 2021).

While a small number of studies demonstrate that different forms of intervention methods yield improved performance, generalization of results to all children with CVI is not clear-cut. Two children with similar etiology, similar underlying causes, of a similar age, and at a similar level in relation to learning and developmental milestones, can see and understand their world very differently. One child, for example, may use primarily visual search techniques while the other may rely more heavily upon touch. Assessments require highly trained and experienced practitioners who understand a wide range of strategies yet have the confidence to listen to the student and those who know the student well to work out collaboratively the best approaches to try. There is no right or wrong; each child is different, and support can only be a journey, not the outcome of an assessment process.

Comprehensive assessment outcomes form the building blocks for the implementation of specific educational interventions whose priorities and goals in the US are set by IEP or IFSP teams of professionals and family members. Moreover, learners with CVI, including those who are falling behind on their academic and behavioral goals and outcomes, need approaches to intervention that are validated, effective, and provide access to the highest quality instruction in the least restrictive environment. Additionally, the use of established methods must incorporate newly-developed and promising practices that address the range of diverse needs of students who have CVI including those transitioning to higher education and adult rehabilitation services.

It is increasingly clear that emerging educational and (re)habilitation tools that are valid, reliable, meaningful, and measure intervention outcomes need to be sensitive to incremental changes in vision and visual-perceptual functions as well as the use of vision and other sensory systems in daily and school tasks to document and monitor change over time (Lueck & Dutton, 2015). This may require the use of detailed observations and record-keeping systems in addition to the use of formal and informal assessment tools. Evidence-based measures that are sensitive to effects of interventions and their outcomes, such as those now used in occupational therapy (Caire et al., 2022; Harpster et al., 2019; Turner-Stokes, 2009; Verkerk et al., 2023) still need to be developed and disseminated to address functional changes associated with CVI, including the use of functional vision as well as more broad-based functional outcomes (Lueck et al., 2021).

Because CVI is so varied in its expression, the types of educational interventions required are extensive and need to address multidimensional concerns that go beyond vision and visual-perceptual skills. This includes vision use in functional tasks, decoding multisensory information, compensatory strategies, consideration of CVI's broader impact on other domains of function (Bauer et al., 2023; Ben Itzhak et al., 2021; Chorna et al., 2017; Lueck & Dutton, 2015; Morelli et al., 2022; Overbeek et al., 2022; Philip, n.d.; Pilling, 2023; Weden et al., 2022). Moreover, interventions are not just visual or related to other domains of development or functional skills; many with CVI have developed issues with confidence, have anxiety, social difficulties and mental health problems including depression. These social and emotional challenges need to be a part of any intervention plan, not separate from it (Lueck et al., 2021).

In the absence of many validated interventions specific to CVI, educators and interventionists need to blend their personal judgment with student responses and data collected from ongoing progress monitoring procedures. Monitoring ongoing change in learning outcomes is now seen as an important activity in all educational environments with progress monitoring data collected to analyze whether more or less intervention is needed. (Dale et al., 2022; Office of Special Education Programs, U.S. Department of Education, 2018). These multiple data sources inform modifications to intervention strategies and promote flexibility to ensure that the learner is benefitting from educational services (i.e., they are meeting their educational goals and potential). The process of implementing interventions is not about adhering to rigid curricula or instructional tools, but rather, about engaging in data-driven problem-solving processes that are specific to individualized needs related to CVI and its manifestations (Office of Special Education Programs, U.S. Department of



Education, 2018). Furthermore, even though students with CVI may present as having vision sufficient to provide access to visual information, it is important that existing IEP procedures also consider the quality of the information that can be retrieved and processed. Consequently, the use of alternative learning media including braille as well as assistive technology services and devices may be more productive and meaningful.

The success of supports or interventions for students who have CVI is often measured by change in performance and monitoring the trajectories thereof. When a child's progress does not follow a neat trajectory within a set time, the intervention may not be working as intended. In fact, more time might be needed, and success might need to be measured in different ways that take into account a student's motivation across the age-span. For example, some suggested interventions may be rejected when they do not mesh with an older student's self-determined needs. Monitoring 'success' around improved levels of purported deficient performance in relation to a typical students could be considered discriminatory and certainly limits potential avenues of more welcome and effective support (St Clair Tracy, 2023, personal communication)

A multidisciplinary team comprised of members knowledgeable about CVI is considered the most effective to implement assessment and intervention strategies for students who have CVI. Often such teams, with members knowledgeable about CVI, are not readily available. Yet, even when a team is available, coordination and communication among the range of professionals may be inadequate, affecting opportunities for referral and consequential discourse among team members. (Boonstra et al., 2022). As such, many students and their families are unsure of ways to address the many concerns that arise over time with CVI, and they may not even be sure that their concerns are due to CVI. When diagnosis, assessment, and interventions are difficult to obtain, undue pressure is placed on the students and their families. They may need to become their own advocates, learning about the condition on their own without formal support, and feel compelled to 'shop around' for appropriate assistance. Families with limited access to resources may be disproportionately impacted since they cannot afford to seek outside consultations, may not participate in social media support systems, or may be limited in their time to investigate additional supports and resources (McDowell, 2021; Oliver et al., 2023).

When medical and education assessment results are relayed clearly, families are empowered to understand fully their children's unique diagnoses and prognoses rather than be confounded by them. They can then advocate for their children and work in tandem with the IEP or IFSP and medical teams to develop optimum intervention approaches (McDowell, 2021; Oliver et al., 2023).

### **With the above in mind, what are some potential ways that policy change at various levels can help solve these issues?**

Because awareness of CVI and its various manifestations among healthcare professionals, educators, and communities plays a significant role in many aspects of the lives of children with CVI, including the ways in which parents experience raising a child with CVI (Oliver et al., 2023), it is imperative that policy change surrounding visual impairment occurs at multiple levels, from the local legislature to international policy.

At a fundamental level, global definitions of "visual impairment" need to be shifted away from those exclusively seen as "20/200 (1.00 logMar) visual acuity or less in the better eye with best correction or peripheral field no greater than 20 degrees" to encompass visual dysfunctions that impact one's ability to use vision to access the environment in a meaningful manner.

Similarly, diagnostic codes in the ICD 11 (2018) and ICF need to be updated to acutely reflect CVI. Currently, ICD codes used for patients with CVI classify visual impairment into two groups: distance and near-presenting vision impairment. Other codes are for "cortical blindness", which as outlined above, is not an appropriate term for those with visual dysfunction secondary to brain injury, damage, or malformation.

When these medical definitions for visual impairment become inclusive of people who have CVI, mechanisms also need to be in place for implanting these new definitions across education, (re)habilitation, social security, veteran's affairs, and other agencies who work with these individuals at the level of intervention services.

Currently, CVI is not or is minimally part of the mandatory training for most medical professionals, including ophthalmologists, leading to a lack of exposure and confidence in evaluating, diagnosing, and medically treating those with CVI (Harpster et al., 2022). This may be particularly evident for those in whom visual fields

and acuity are within typical levels (Goodenough et al., 2021). More intensive training in CVI by professionals in other fields such as optometry, education, occupational therapy, speech-language pathology, orientation and mobility, and more is also needed. A clear first step would be to implement mandatory training in CVI that encourages a multidisciplinary approach to evaluation and screening in order to fully appreciate how vision, visual behaviors, cognition, communication, and mobility may be impacted.

As a step in the right direction, some initiatives have recently been implemented in the US, UK, and EU.

In the US, the National Eye Institute (NEI) released its Strategic Plan in 2021, which included an initiative for CVI (National Eye Institute, 2021). This strategic plan will guide the provision of federal government resources for research leading to improved scientific understanding, clinical care, and the sociological impacts of vision disorders in the United States. The recognition of CVI by the NEI in the Strategic Plan is a milestone event in the advancement of CVI research leading to improved clinical care for children with CVI, emphasizing the need for more research to optimally diagnose and treat children with CVI, as well as to understand the natural course of CVI, including potential changes to neural networks associated with maturation and the implementation of (re)habilitation strategies. In addition, formation of the NEI's Office of Data Science and Health Informatics was announced to aid in the development and formation of a registry for individuals with CVI. The registry could include multiple sources of data, such as functional and behavioral outcomes, as well as imaging data. Such a registry is seen as an essential first step in realizing the research goals previously described, recognizing the interdisciplinary nature of CVI research and patient care (National Eye Institute, 2021). In the UK, Scotland has published a guide outlining the consistent diagnosis of CVI (<https://www.vincyp.scot.nhs.uk/wp-content/uploads/2021/12/VINCYP-CVI-Diagnostic-Guideline-2021.pdf>). This guide is meant to be used by all health professionals in Scotland involved in the clinical management of children with CVI.

Along these lines, the European Academy of Childhood Disability (EACD) is currently sponsoring a multinational project involving clinicians and researchers from the UK, EU, and US which seeks to develop evidence-based clinical practice guidelines for CVI (<https://www.eacd.org/EACD-Consensus-Projects>). Diagnostic guidelines have recently been published by a multidisciplinary group from the Netherlands (Boonstra et al., 2022) that provides support for these much-needed changes in international policy.

In conclusion, we urge the field to consider implementing a definition of CVI and of visual impairment that are inclusive to accommodate all forms of CVI. We recommend support for multidisciplinary teams encouraged to work collaboratively and with clear lines of communication to address the needs of individuals who have CVI. And we urge the creation, development, and implementation of assessment and intervention methods that are evidenced-based and multidimensional, evolving over time as additional needs of individuals who have CVI, including those with more subtle sequelae of the condition, are identified. Without these critical elements, individuals with CVI and their caregivers will be excluded from receiving diagnoses and services, and thus denied the support they need to thrive.

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