CVI: The Conversation Continues...¹

Anyone who has spent time researching CVI knows that there are a variety of names and definitions for this neurological visual impairment. The fact that it is caused by an incident to the brain complicates the search for one definition because there is much that we still do not know

about the brain. There is a need to organize what we currently understand about CVI leaving room for new information as it is researched and made available. There are strategies, products, assessments, and resources that are appropriate for some CVI students, but not for others. Establishing a classification system would allow teachers and parents to understand more easily what materials they should be looking at to help in the education of their student. Dr. Lea Hyvarinen and August Colenbrander write about the need for an international classification in their chapters of the book edited by Gordon Dutton and Martin Bax titled "Visual Impairment in children due to damage to the brain."

Those working with children diagnosed (and many who remain undiagnosed) with CVI understand that the more we learn about this neurological visual impairment the more complicated the conversation becomes.



In 2007 when AFB Press released "Cortical Visual Impairment: An Approach to Assessment and Intervention" written by Christine Roman-Lantzy our field has been able to use the CVI Range to assess student functioning levels, monitor progress on the CVI Resolution Chart and provide recommendations and interventions for the team working with the child. The book has become an invaluable resource for educators and families working with this population. But, there are learners that may not be identified by this assessment alone. Dr. Gordon Dutton writes "The severity of CVI can range widely between profound and disorders of visual perception only. The subject is complex, but it is important for the educational assessment team to address the issue fully when assessing an affected child and planning management" (Dutton, 2013). Those students presenting disorders of visual perception, often go undiagnosed because their needs

¹ https://cvi.aphtech.org/

may be hidden. These children may be academic, traveling independently, but facing many challenges for which accommodations are necessary.

Dutton and Lueck (2015) offer a description of three groups of children in their AFB book "Vision and the Brain: Understanding Cerebral Visual Impairment in Children."²

- 1. Children with profound visual impairment due to CVI, many of whom have additional disabilities
- 2. Children who have CVI who have functionally useful vision and cognitive challenges,
- 3. Children with CVI who have functionally useful vision and who work at or near the expected academic level for their age group.

"We should be cautious not to assume that all children with CVI exhibit the same behaviors. The diagnosis means different things for different children; the effects depend on factors such as how extensive and severe were the insults to the brain, the developmental period during which the insult occurred, the child's previous experience, the presence or absence of additional disabilities, medications being taken, and the child's motivation. Some individuals with CVI have no observable visual responses: others have occasional responses to stimuli, whereas still others have a significant amount of usable vision."³

"Vision impairment due to damage to the brain is common in children. Those affected can be identified and managed well by being alert to the possibility that it may be present, and carefully taking a history and assessing all in whom it is suspected."⁴

"The body of current medical literature concerning conditions associated with a diagnosis of CVI is most likely incomplete. Medical investigators are just beginning to gather consistent data regarding the causes and conditions associated with CVI. It is important to note that not all researchers agree on the full range of causes, the prognosis or even the proper diagnostic label used to describe vision loss due to brain damage. What is needed is more cooperation and dialogue between members of medical and educational disciplines, and specifically among ophthalmologists, neonatologists, neurologists, and other pediatric specialists, in the hope that

² Roman-Lantzy, C. (2007). *Cortical visual impairment: An approach to assessment and intervention.* New York, NY: AFB Press. Dutton, G. N. (2013). Types of impaired vision in children related to damage to the brain, and approaches towards their management. *Journal of the South Pacific Educators in Vision Impairment, 6(1), 14-30.* Dutton, G., & Bax, M. (Eds.). (2010). *Visual Impairment in children due to damage to the brain: Clinics in developmental medicine.* London, England: Mac Keith Press.

³ Morse, M. T. (1999) Cortical visual impairment: Some words of caution. RE:VIEW, 31(1), 21-26.

⁴ Dutton, G. N. (2013). Types of impaired vision in children related to damage to the brain, and approaches towards their management. *Journal of the South Pacific Educators in Vision Impairment, 6(1), 14-30*.

timely identification will facilitate appropriate referral to specialists who can undertake early intervention."⁵

"It is important to note that many earlier concepts about brain functions were incorrect, which is not surprising because of the extreme complexity of the central nervous system. However, several conclusions can be drawn from recent advances that would benefit professionals who are providing a variety of services to children and adults with visual disorders. Connectivity studies have clearly proved that vision is more complex than was previously thought, and it is not isolated from the other senses but works in close liaison with them. The brain is plastic at any age, but remarkably so during the early years of life. Therefore, exposure to meaningful experiences and age-dependent activities will not only strengthen the visual networks, but will modify the other senses in compensation for the loss of vision."⁶

"These parents reported that the primary reason they had difficulty obtaining an appropriate education for their children was physicians' and teachers' lack of understanding, knowledge, and training with regard to CVI."⁷

"The brain is intricate in its design and function. Neuroscientists and neuropsychologists are revamping concepts and principles that are related to brain function and vision as more information is obtained and understood. The changes that are emerging from brain research are altering our understanding of cortical or cerebral visual impairment (CVI) in children. In addition, injury to the brain can result in functional manifestations that are complex and multifaceted. These functional manifestations are related to the extent, location, and time of onset of the brain lesions, but the precise effects of these injuries cannot be readily and fully predicted in children from the brain lesions themselves. For example, we have no idea of the ways in which areas of the brain that are intact in young children who have brain damage assume the functions of damaged areas owing to the plasticity of the brain. Thus, an understanding of recovery mechanisms for CVI in children and of the effects of intervention is in its infancy. As a result, our understanding of the nature of CVI in children must be open and flexible as we incorporate and learn to apply an ever-evolving knowledge base. We must understand the issues surrounding CVI, embrace their complexity and lack of closure, and determine directions for the effective diagnosis and treatment of children with CVI from medical and educational perspectives."⁸

⁵ Roman-Lantzy, C. (2007). Cortical visual impairment: An approach to assessment and intervention. New York, NY: AFB Press.

⁶ Jan, J. E., Heaven, R. K. B., Matsuba, C., Langley, M. B., Roman-Lantzy, C., & Anthony, T. L. (2013). Windows into the visual Brain: New discoveries about the visual system, its functions, and implications for practitioners. Journal of Visual Impairment & Blindness, 107(4), 251-261.

⁷ Jackel, B., Hartmann, E., & Wilson, M. (2010). A survey of parents of children with cortical or cerebral visual impairment. Journal of Visual Impairment and Blindness, 104(10), 613-623.

⁸ Lueck, A.H. (2010). Comment: Cortical or cerebral visual impairment in children: A brief overview. Journal of Visual Impairment and Blindness, 104(10), 585-592.