

CVI from an Integrated, International, Interdisciplinary Perspective

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Sander Zuidhoek, PhD, is a children's neuropsychologist at Royal Dutch Visio and chairman of the national Expertise Group on Cerebral Visual Impairment at Royal Dutch Visio. He is an expert on CVI, visual processing and haptic spatial perception. He is a (co-)author of several journal articles and chapters on haptic spatial perception, CVI and visual imagery. He is lecturer and education coordinator in the Psychology Master program at Tilburg University and lecturer in two post-Master educational programs of the Rijksuniversiteit Groningen.



Symposium abstract

It has been well documented that Cerebral Visual Impairment (CVI) is now the leading cause of childhood visual impairment within Western countries. Unfortunately, CVI is still poorly understood and reducing CVI-patients' problems and restrictions in daily life has proved a difficult task, in many – if not all - countries. One of the reasons is that CVI is a multifaceted disorder for which diagnosis as well as effective intervention requires the integrated knowledge of many disciplines and professional perspectives. Another is that countries differ in their health care and educational infrastructures and as such in their potential to take up the challenges that the care for CVI-patients poses. Moreover, the relevant factors underlying the prevalence of CVI are largely unknown. In the current symposium we aim to provide a broad but integrated view of these issues by presenting experts of different disciplines and international backgrounds. It starts off with a first-hand account of the visual experiences most commonly reported by CVI-patients and offers a deeper explanation of these experiences using an elaborate, innovative neuropsychological framework which identifies disorders in visual selective attentional processes as their culprit. After this, a comprehensible and practical picture of the complex issues involved in diagnosing CVI-diagnosis is presented, followed by a report on the challenges that CVI poses in educational settings. Lastly, evidence suggesting a relationship between CVI and social deprivation is presented and discussed as a public health concern.

Lectures:

- A World of Visual Uncertainty (Nicola McDowell)
- The Importance of ICF and the Correct Neuropsychological Explanations for Successful Rehabilitation of CVI-patients (Sander Zuidhoek)
- CVI: the importance of diagnosis and differential diagnosis with other developmental conditions (Sylvie Chokron)
- Meeting the Needs of Children with Cerebral Visual Impairment in Educational Programs (Amanda Hall Lueck)
- Where is Childhood Cerebral Visual Impairment: A Public Health Concern? (John Ravenscroft)

1. A World of Visual Uncertainty

Nicola McDowell, MSpTchg

Resource Teacher Vision and Orientation and Mobility Specialist; Blind and Low Vision Education Network New Zealand (BLENNZ)

Try to envisage living in a world where, although you think you have good visual skills, your brain is not effectively processing all of the visual information as you engage with the world around you. It's pretty hard to comprehend right? Now extend this further and imagine that this difficulty is not only unknown to you, it is also invisible to those around you. So although everyone can see that you are having difficulties with different aspects of everyday life, no one is able to correctly attribute these issues as being related to your vision. Your difficulties in crowded and cluttered environments are unexplainable and the fact that you are unable to process visual and auditory information at the same time is incomprehensible to everyone, including yourself. But the most misunderstood aspect of all, is the high levels of anxiety and stress that are so all consuming and overwhelming that at times, you feel that you cannot function at all.

Unless of course your difficulties are diagnosed as CVI, as having this knowledge can change your life. Well this was my experience anyway. After living with CVI for seventeen years following a brain haemorrhage, getting the diagnosis of CVI finally allowed me to make sense of my world again. This knowledge also enabled me to gain a deeper understanding of my impairment, which empowered me to develop strategies to help alleviate some of the effects of this condition. This has meant that I am now able to approach situations confident in not only my ability to handle challenging visual scenes, but also more aware of my limitations. This understanding has also had a major impact on my self-esteem and confidence, which highlights why an early diagnosis is so vital for children with CVI.

2. The Importance of ICF and the Correct Neuropsychological Explanations for Successful Rehabilitation of CVI-patients

Sander Zuidhoek, Ph.D.

Children's neuropsychologist of Royal Dutch Visio; Chairman of Royal Dutch Visio's Expertise group on CVI; Lecturer and education coordinator at Tilburg University

As illustrated by the first speaker, the effects of CVI on daily life functioning and psychological health can be profound. An important factor is that CVI is unknown and poorly understood. Over the last 25 years Royal Dutch Visio has been developing an interdisciplinary approach of CVI based on WHO's ICF and a strong neuropsychological model which has been successful in explaining and diagnosing different types of CVI and rehabilitating CVI-patients. ICF advocates a broad approach to finding the causes of the problems and restrictions in daily life, and allows us to consider all potential causes, not just the visual ones. In addition, it identifies protective factors – which are essential for rehabilitation – as well. The problems and restrictions that do have a visual cause, can result from low visual functions, high visual functions and/or general cognitive functions. Although the low visual functions are well-known and undisputed, the high visual functions are generally poorly understood and have been a matter of debate. Over the years we have developed a comprehensive, hierarchical model in which the high visual functions are identified as well as understood in their interrelationship with low visual functions and general cognitive functions. Moreover, it offers a profound understanding of the neuropsychological mechanisms underlying the visual experiences most commonly reported by CVI-patients, where other models fail to do so: central visual crowding and simultanagnosia (both described by the first speaker) are commonly regarded as *perceptual* disorders. Our model, however, identifies them as disorders in the stage *preceding* the perceptual stage: that of *visual selective attention* (i.e., local and global visual selective attention, respectively). The current talk stresses the correct neuropsychological explanation rather than a label describing the problem (like “crowding” or “simultanagnosia”) is crucial for our understanding of CVI and as such for successful rehabilitation.

3. CVI: the importance of diagnosis and differential diagnosis with other developmental conditions

Sylvie Chokron, Ph.D.

Head of Vision and Cognition Unit; Fondation Ophtalmologique Rothschild & Laboratoire de Psychologie de la Perception, Université Paris-Descartes

Cerebral visual impairment (CVI) has become the primary cause of visual impairment and blindness in children in industrialized countries. Its prevalence has increased sharply, due to increased survival rates of children who sustain severe neurological conditions during the perinatal period. CVI impedes visual detection, attention, recognition and/or exploration and interferes not only with learning but also with the global interaction (social and affective) between the child and the external world. In this way, disorders of higher visual function, such as CVI, can also be easily confounded with psycho-affective or developmental disorders. There is thus a need to specifically investigate the visual function, as well as the psycho-intellectual, cognitive and social disorders, associated with CVI in at risk children.

This transdisciplinary approach is necessary for clinical as well as basic science reasons: (1) to avoid misdiagnosis in children with severe learning or behavioural disabilities; (2) to prevent learning as well as social and major affective disorders consecutive to CVI, (3) to refer children with CVI to specific and adapted rehabilitation programs; (4) to understand the complex link among visual, neuropsychological, social and psychological functioning.

In the present talk, we define CVI and how this impacts on visual function, cognitive function and social interaction. This talk underlines why there are both clinical and theoretical reasons to disentangle CVI and other developmental disorders, and to categorise the features with more precision. In order to offer the most appropriate rehabilitation, we propose a systematic and rapid evaluation of visual function in at-risk children who have survived preterm birth, perinatal asphyxia or any other neurological condition, whether or not they have been diagnosed with other developmental disabilities.

4. Meeting the Needs of Children with Cerebral Visual Impairment in Educational Programs

Amanda Hall Lueck, Ph.D.

Professor Emerita of Special Education & Communicative Disorders at San Francisco State University

Work in the area of CVI in children has been rapidly increasing. With advances in knowledge comes the need to translate available information effectively to identify, assess, and instruct individual children. Once medical concerns have been addressed, teachers and families need to know what to do to optimize the lives of children under their care to ensure that the children have the skills and understanding they need to determine, as independently as possible, the direction of their lives, what has value for them, and feel appreciated in their roles in their family and communities. In addition, with the increased and compelling need for appropriate education programs for children with CVI, many issues arise pertaining to existing service delivery systems and the preparation of professionals who work with this population of children. Under discussion will be issues associated with identification, entitlement to services, assessment and intervention methodology, universal design for learning, training of personnel, and availability of resources. The topics under review are ones that will propel professionals to engage in collaborative solutions for this population of children who experience their world in unique ways and who require innovative approaches for their education and care.

5. Where is Childhood Cerebral Visual Impairment: A Public Health Concern?

Professor John Ravenscroft

Chair of Childhood Visual Impairment, University of Edinburgh

It has been well documented that Cerebral Visual Impairment (CVI) is now the leading cause of childhood visual impairment within Western countries. Equally noted is the prevalence rate of childhood CVI has increased with the advances of neonatal expertise and better differential neurological diagnosis. However, what has not been reported in the literature is the relationship of childhood CVI to social deprivation. This paper will present data from the Visual Impairment Scotland (VIS) dataset, a longitudinal (12 years) notification incidence study using 183 patient notifications of childhood CVI. The Scottish Index of Multiple Deprivation (SIMD) identifies small area concentrations of multiple deprivation across all of Scotland in a consistent way. SIMD ranks small areas (called data zones) from most deprived (ranked 1) to least deprived (ranked 6,976). There are 6,966 data zones in SIMD which equates to 760 people per data zone. Using the SIMD as a standardised measure of

deprivation in conjunction with the VIS data set we are able to identify by matching postcodes within the SIMD and VIS data sets to determine the SIMD index of every child notified to VIS. A statistical correlation of childhood CVI and all children with visual impairment (minus CVI) was performed with the SIMD index. We found, as reported previously in the literature, that overall there is no correlation of childhood visual impairment with social deprivation, but when we examine only childhood CVI we find a significant correlation particularly in the most deprived areas of Scotland. The results of this finding are mapped geographically within Scotland and are discussed in terms of a public health concern.