2009

A Team Approach to Cortical Visual Impairment (CVI) in Schools

Donna Shaman
University of North Dakota

A TEAM APPROACH TO CORTICAL VISUAL IMPAIRMENT (CVI)

IN SCHOOLS

Donna Shaman, OTR/L

Advisor: Cindy Janssen, MOT, OTR/L

A Scholarly Project

Submitted to the Occupational Therapy Department

of the

University of North Dakota

In partial fulfillment of the requirements

for the degree of

Master's of Occupational Therapy

Grand Forks, North Dakota
May 2009

This Scholarly Project Paper, submitted by Donna Shaman in partial fulfillment of the requirement for the Degree of Master's of Occupational Therapy from the University of North Dakota, has been read by the faculty Advisor under whom the work has been done and is hereby approved.

Cindy Janssen, MOT, OTR/L
Faculty Advisor

May 11, 2009
Date

PERMISSION

Title	Team Approach to Cortical Visual Impairment (CVI)
Department	Occupational Therapy
Degree	Master's of Occupational Therapy

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ABSTRACT

Cortical visual impairment (CVI) is presently the fastest growing cause of visual impairment in children. The influx of children with CVI entering school districts requires Individualized Education Program (IEP) teams to gain expertise about CVI and learn best practices to work with these children. CVI experts agree that a collaborative transdisciplinary team can best serve the complex needs of the children. Written by an occupational therapist, this project designs a CVI manual, *A Team Approach to CVI in Schools,* which reviews current literature and provides support for client centered, occupational based education for children with CVI. The literature review points to a shortage of research-based guidance for working with children with CVI. Although recent CVI literature offers new strategies for improving the vision of children with CV, this CVI manual fills the need for a school guide that focuses on the children's broad school participation by addressing the transactional components of child, context, occupation, and teacher/therapist in designing effective school programs. The manual strives to build capacity of school IEP teams to work collaboratively and effectively with children with CVI by increasing the teams' knowledge base about CVI and helping the children participate fully in school. Best practices in education for children with CVI are presented in the areas of school evaluation, programming, and student engagement in meaningful activities within daily routines.

CHAPTER I

INTRODUCTION

Children with cortical visual impairment (CVI) exhibit limited visual or visual motor skills secondary to damage to the visual areas of the brain. The children cannot effectively make sense of visual images despite normally functioning eyes (Good, et al., 1994). CVI is the primary cause of pediatric visual impairment in the western world, secondary to advances in neonatal medical care (Hoyt, 2003; Ketpal & Donahue, 2007). Until recently, there have been no specially designed education programs for children with CVI, despite advances in brain research and CVI diagnostics. Until the past few years, the assumed educational outcome for a child with CVI was pessimistic and families and educators were resigned to wait for the child's vision to either spontaneously improve or worsen.

The purpose of this scholarly project is to develop a CVI manual for IEP teams who work with children who have CVI. This manual will help to fulfill the need for specially designed education programs to promote school participation of children with CVI. Writing a manual about CVI for school based Individual Education Plan (IEP) teams is best begun with optimism and hope that an education program can affect positive change. During the past few years, Dr. Roman-Lantzy has promoted a promising and innovative approach to motivate and assist children with CVI to optimally use their vision, build new visual pathways in the brain, and ultimately improve visual capability.

Roman-Lantzy's program focuses on improving the child's vision through overlaying adaptations to the child's environment and educational materials in order to help children with CVI make sense of what they see (Roman-Lantzy, 2007).

This CVI manual, *A Team Approach to CVI in Schools,* offers current knowledge about CVI and guides IEP teams to engage children with CVI in meaningful school occupations to support their school participation, enjoyment, and well-being. Special focus is placed on increasing the child's capacity to play and develop social connections.

The field of occupational therapy (OT) supports client-centered and occupation-based practice that emphasizes the interrelationship and interdependence of the client, context, and occupation. The ultimate goal of OT overarches the educational goal for children with CVI, which is to improve the child's participation in school by engaging in meaningful activities of education, work, play, leisure, and social relationships. The development of the CVI manual, *A Team Approach to CVI in Schools,* is supported by current OT theory and practice. Although the language and focus of the CVI manual addresses the broad learning needs of the whole IEP team, the underlying beliefs of the manual are congruent with the core values of OT. The Occupational Therapy Practice Framework, which supports health and well-being through engagement in occupation and emphasizes the importance of a therapeutic relationship with the child, guided the development of the CVI manual (AOTA, 2008). Additionally, two related OT models, Person-Environment-Occupation Model (PEO; Dunbar, 2007) and Canadian Model of Occupational Performance (CMOP; Law, Polatajko, Baptiste, & Townsend, 1997) guide the foundational beliefs underlying the manual.

A Team Approach to CVI in Schools was written to help the child with CVI learn to see better, engage meaningfully in school occupations and increase his/her school participation and sense of well-being. Additionally, the CVI manual offers the IEP team the opportunity to gain expertise and confidence to work collaboratively and effectively, and to increase each team member's meaningful and enjoyable engagement with the child. The author strives to promote OT by widely disseminating an accessible, broad-based CVI manual that addresses the teaching needs of an IEP team while integrating and affirming the core tenets of OT.

Chapter II, Review of the Literature, broadly explores current research in CVI including etiology, prognosis, diagnosis, and educational perspectives. The review of the literature points to the need for IEP teams to collaborate to develop effective school programs to increase participation of children with CVI. Chapter III, Method, examines the development of the CVI manual by summarizing critical CVI research underlying the expanding possibility of vision remediation and the need for broader occupational perspectives for working with this population. Also explored is the rationale for developing a CVI manual, written for IEP teams, using common terminology, while grounded in current OT models and framework. Chapter IV, Product, presents the CVI manual, *A Team Approach to CVI in Schools* in its entirety. Chapter V, Summary, explores future expansion and research needs, suggestions for expanding training for IEP teams, and ideas for promoting and disseminating the CVI manual so as to ultimately reach school based IEP teams that work with students with CVI.

CHAPTER II

LITERATURE REVIEW

Introduction

Cortical visual impairment (CVI) is currently the leading cause of visual impairment in children in the western world with more children becoming diagnosed with CVI than all other pediatric visual diagnosis combined (Hoyt, 2003; Ketpal & Donahue, 2007). CVI is defined as a non-ocular neurological disorder caused by damage to the central nervous system (Good, et al., 1994). In lay terms, CVI results from damage to visual areas of the brain, rather than damage to eye structures. Over the past decade, advances in brain research and brain imaging have spurred new CVI assessments, classifications systems, and educational strategies. CVI is a broad umbrella containing a wide range of visual disorders and associated problems. CVI significantly affects all areas of a child's development and his/her perceptions of the world.

Aggregating and analyzing current research can help guide education and rehabilitation practitioners to better understand the underlying causes of CVI and implement best practices to work with children with CVI. While it is essential to understand causes and the common behavioral characteristics of children with CVI, it is also crucial to recognize that each child with CVI has a unique visual system and each has individualized educational needs. Understanding a child's complex visual skills, clusters of disabilities and developmental needs is paramount to developing a meaningful education program (Groenveld, 1994).

As compared with the relatively abundant medical literature focusing on the causes and diagnosis of CVI, until the past couple of years, there has been relatively little information available to teachers and therapists, perhaps because professionals generally assumed that the visual capacity of these children could not be improved. This literature review is written for the purposes of informing parents and IEP teams of the promising developments in the field of CVI and for parents and professionals to gain comfort and confidence working with the children. Of special interest in the literature is the unified view of experts that recommend a collaborative team approach based on children's needs for consistency, routine, and familiarity.

Incidence of CVI

With sophisticated perinatal medical care resulting in increased survival rate of premature and very sick term babies, more infants are diagnosed with major neurological deficits, including CVI. Cortical visual impairment has become the leading cause of visual impairment in children in the western world (Hoyt, 2003; Ketpal & Donahue, 2007; Khan, O'Keefe, Denny, & Nolan, 2007). The prevalence of CVI has been rising over the past few decades, from 36 per 100,000 children in the late 1980's to 161 in 100,000 children in 2003 (Hoyt, 2003).

The American Printing House for the Blind (APH) oversees *Babies Count: The National Registry for Children with Visual Impairments, Birth to 3 Years,* a national registry that collects data on the prevalence and causes of visual impairment. Between

January 2000 and December 2004, the Babies Count National Registry collected data on 2,155 visually impaired children from the 29 states that participate in the National Registry. The most prevalent diagnosed visual condition during this timeframe was CVI (N= 509, 23.6%; Hatton, Schwietz, Boyer, & Rychwalski, 2007). Burt Boyer, Coordinator of Babies Count Project (personal communication, November 5, 2008) stated that an initial analysis suggested that 24% have a diagnosis of CVI from the approximate 5,000 babies registered during the past seven years with the Babies Count Project. From the total records of 7200 outpatients seen in their pediatric ophthalmology clinic, Huoa, Burden, Hoyt, and Good (1999) ascertained that 2.4% of the children had a diagnosis of CVI.

Definitions of CVI

Until recently, cortical blindness was the common terminology found in medical literature. The term referred to blindness caused by bilateral damage of the occipital cortex. The term cortical visual impairment is now commonly used because a child with CVI rarely is completely blind. Additionally, even though a child may initially lack visual behaviors when first diagnosed, it is not possible to determine visual outcome as most children with CVI experience visual recovery over time (Hoyt, 2003). In the literature, there are multiple definitions of cortical visual impairment, with notable differences between medical and educational professionals. Khetpal and Donahue (2007) defined CVI as the decrease of visual function without damage to the anterior afferent visual pathways or eye structures. The American Printing House for the Blind-Cortical

Visual Impairment website (APH-CVI, 2009) provides both medical and educational definitions. The definition of CVI for medical purposes is:

> Cortical visual impairment (CVI) may be defined as bilaterally diminished visual acuity caused by damage to the occipital lobes and or to the geniculostriate visual pathway. CVI is almost invariably associated with an inefficient, disturbed visual sense because of the widespread brain disturbance (APH-CVI, 2009).

The definition of CVI for educational purposes is:

> Cortical visual impairment (CVI) is a neurological disorder, which results in unique visual responses to people, educational materials, and to the environment. When students with these visual/behavioral characteristics are shown to have loss of acuity or judged by their performance to be visually impaired, they are considered to have CVI (APH-CVI, 2009).

Additionally, APH Federal Quota Census specifies a new category for children with CVI. The category, Functions at the Definition of Blindness (FDB) is used for children with brain injury or dysfunction, when visual acuity cannot be measured by using the Snellen chart.

> Functions at the Definition of Blindness *(FDB)* is a new category indicating blindness due to brain injury or dysfunction. A student whose visual performance is reduced by a brain injury or dysfunction may be considered blind for educational purposes when visual function meets the definition of blindness as determined by an eye care specialist or neurologist. Students in this category

manifest unique visual characteristics often found in conditions referred to as neurological, cortical, or cerebral visual impairment (APH-CVI, 2009).

With new brain research revealing an increasing complexity of neural pathways and areas of the brain related to vision, the term CVI is also used to describe a myriad of higher-level visual disorders. As a result, some CVI experts are promoting that CVI be subdivided into distinct types, while others are considering CVI a spectrum disorder (Groenveld, 1994).

There is ongoing debate regarding the terminology of CVI. Many authors argue that cortical visual impairment is not an accurate term, as the visual cortex is rarely damaged to the exclusion of damage to white matter pathways (Dutton & Jacobson, 2002; Hoyt, 2003; Ketpal & Donahue, 2007). For this reason, some researchers have chosen alternate terminologies including cerebral visual impairment (Dutton & Jacobson) and cognitive visual impairment (Saidkasimova, Bennett, Butler, & Dutton, 2007). Brodsky, Fray, and Glasier (2002) recommended dividing CVI into two subtypes, dependent on the infant's full term or preterm gestational status, because the symptomatology is notably different for these two subgroups. Cortical visual damage of term babies generally result in a common group of symptoms such as horizontal conjugate gaze deviation and exotropia, whereas subcortical visual loss from preterm injury relate to symptoms such as tonic downward gaze, esotropia, and optic nerve hypoplasia. Some researchers use the term cortical visual impairment very broadly to include a wide range of other vision related disabilities such as motor apraxia and visual inattention (Hoyt, 2003). Other researchers have opted to reserve the term cognitive visual dysfunction for deficits in higher level visual processing (Good, Jan, Burden, Skoczenski, & Candy, 2001). Cohen-Maitre and Haerich (2005) recommended changing the term to developmental visual agnosia (DVA) because so many children with CVI exhibit various types of agnosia. Hyvärinen (2005) chose the term brain damage related vision loss. She took issue that CVI sounded like a medical diagnosis. More accurately, CVI is a broad statement of visual performance deviated from the norm.

Despite new understanding of the brain's complex and critical role in vision, national and international visual impairment classification systems have not updated their classifications beyond the antiquated categories based on visual acuity and visual fields (Edelman, et al., 2006). Loss of acuity continues to dominate the framework of many eye clinicians, diagnostic categories, and reimbursement systems (Jan, 1998). New classification systems should include domains of functional and neurological vision and visual processing (Jan & Freeman, 1999). Jan, Good, and Hoyt (2004) have stressed the importance and the challenges of developing an international classification system by utilizing consistent universal criteria to promote international comparisons of incidence and types of visual impairment. Although researchers generally agree that there is a need for a unified classification system for neurological visual disorders, a definitive classification of CVI in children would be difficult to devise, partly because a child's true potential, range of abilities, and participation in the environment may not be evident until the child is older (Jan, et al.).

Etiology and Onset of CVI

The most prevalent cause of CVI is perinatal hypoxia (Hoyt, 2003; Khetpal & Donahue, 2007). In a study of 170 children with CVI, Huoa, et al. (1999) found that perinatal hypoxia was the most common etiology, affecting 38 of the children. Common patterns and symptoms of CVI are associated with the postconceptual age of the child. Full-term infants exhibit damage of the cerebral cortex and premature infants have damage to the periventricular, white matter with little or no cortical damage (Hoyt, 2003). Periventricular leukomalacia is the most common cause of brain damage in premature babies and results in a spectrum of associated and often-severe disabilities, including learning disabilities, spastic diplegia, limitation of lower visual field, mental retardation, and dorsal stream dysfunction (Dutton & Jacobson, 2002). Thinning of the corpus callosum may also occur (Hoyt, 2003). Children with mild PVL tend to have relatively better linguistic skills compared with notably poor visuospatial skills, such as difficulty accessing information on work sheets in school. These children may also tend to be clumsy and trip over objects (Jacobson & Dutton, 2000).

Other causes of CVI include hypoxic-ischemic encephalopathy at term, brain malformation and syndromes, meningitis and encephalitis, neonatal herpes simplex, drugs and poisons, metabolic and neurodegenerative diseases, closed head injury, near drowning, physical abuse, and hydrocephalus (Good et al., 1994). Jan, Groenveld, Sykanda, and Hoyt (1987) reported in their study of children with shunted hydrocephalus that over 50% of the children had significant cortical visual impairment. Almost invariably, PVL is the etiology of premature children with spastic diplegia. A large percentage of children with cerebral palsy have associated visual impairments, with the incidence as high as 70% (Schenk-Rootlieb, van Nieuwenhuizen, van der Graaf, Wittebol-Post, & Willemse, 1992). Epilepsy, especially infantile spasms, can cause temporary or permanent CVI (Good, et al.).

Neurobehavioral Symptoms and Types of CVI

Familiarity with current brain pathophysiology is useful to understand diagnosis and levels of CVI. In the recent past, neurologists considered vision a single sense and a simple process of impressing onto the retina a coded image of the real world, which then transmits to the visual cortex to be decoded. The received codes become associated with previous visual experiences in order for the brain to make sense of the visual image (Groenveld, 1994). Now scientists know that vision is not a single sense but a combination of complex senses that incorporate the entire brain. The brain organizes visual data into specialized areas such as distant vision, contrast, visually directed movement, recognition of faces, and other areas that integrate visual information (APH-CVI, 2009). Multiple, complex physiological pathways are involved in the process of seeing. Anatomically, the retina links to the primary visual cortex through the lateral genicular nucleus where different aspects of the visual image correspond to special areas of the primary visual cortex. The posterior parietal lobe processes the entirety of the visual scene and chooses to attend to certain components. The motor cortex receives visual information for executing accurate movement in visual space. The frontal cortex generates rapid and accurate eye and head movements toward specific targets (Dutton & Jacobsen, 2002).

In 1987, Jan, et al. contributed significantly to the field of CVI when they carefully described common behavioral characteristics of 50 children with CVI. This list of characteristics continue to prove valuable in evaluating children, distinguishing cortical and ocular-based disorders, and promoting improved visual function of children with CVI. In the study, 33 of the children with CVI demonstrated reaching for visual targets, and 11 of these children looked away during the act of reaching (Jan, et al., 1994). Thirty-one of the children characteristically touched objects in order to identify them. Parents in the study stated that their children could better see moving objects compared with static objects and some of the children had better vision while they were traveling in a car (Jan et al., 1987). Only one child exhibited visual self-stimulation, unlike children with ocular abnormalities who frequently exhibit eye pressing.

Many children with CVI hold either objects close to their face or need objects positioned far apart from one another in order to distinguish them, even though the children may have normal acuity (Groenveld, 1994; Jan et al., 1987). Groenveld attributed viewing up-close as the child's visual need to fill up his/her visual field and thus suppress competing background information. Many children with CVI characteristically turn their head away from the object they are looking at or reaching, possibly secondary to sparing of brain damage to certain areas of the brain associated with the peripheral visual field (Good, 1994). Dr. Roman-Lantzy noted during her Portland, Oregon CVI workshop (2005) that some children reserve close vision of one eye to explore the characteristics of an object and the close vision of the other eye to learn the location of the object.

Characteristics of color vision are unique to children with CVI. Groenveld (1994) stated that intact color recognition, common to children with CVI, is due to the high concentration of blood vessels in the corresponding area of the visual cortex. Jan, et al. (1987) noted that many children with CVI preferred bright colors, often the colors red and yellow. They explained that the brain represents color perception bilaterally and diffusely and thereby color characteristics tend to be preserved. Roman-Lantzy (2005) noted that some children with CVI only look at one specific color and some children only look at one specific toy. In various studies, many children with CVI demonstrated stereotypical behaviors of staring at bright objects (Good, et al., 1994). Some children with CVI stare at bright lights, including staring at the sun while outside. In a study of 69 children with CVI, 41 children (59.4%) were light gazers (Jan, Groenveld, & Sykanda, 1990). Presence or absence of other associated neurological disabilities was nearly equal among light gazers and non-light gazers (Jan et al.). Paradoxically, in another study, Jan, et al (1993) found that one third of children with CVI exhibited oversensitivity toward lights (photophobia) probably resulting from damage to the striate cortex and delayed visual adaptation. Interestingly, a few of the same children with light sensitivity were also light gazers, suggesting the intensely compulsive nature of light gazing for some children (Jan, et al. 1993).

Many children with CVI have difficulties with depth perception and distinguishing foreground/background perception, secondary to difficulty suppressing unnecessary information (Groenveld, 1994; Jan, et al., 1993). The mental interpretation of locating oneself in space, especially regarding the dimension of depth is very complex and prone to distortions secondary to cerebral damage (Dutton, et al., 1996). Damage to the bilateral temporal lobes, located anterior to the visual cortex, can lead to impaired or absent perception of movements, so that children can only see static visual environments. Conversely, some children with CVI are visually only able to detect movement in their environment (Dutton & Jacobson, 2002).

Jan, et al. (1987) noted that the children demonstrated inconsistent abilities to utilize visual function which depended on associated factors such as level of fatigue, noise in the environment, involvement in other activities, medication, general health, and seizures. In their study, all the children were able to see relatively better when looking in a familiar environment and initially told what and where to look. Characteristically, the children exhibited decreased visual curiosity and visual attention. In general, visual attention appeared tiring to the children. Some children closed their eyes when listening. Closing their eyes also improved the balance of a number of the children.

Jan, et al. (1987) described the unpredictable and inconsistent visual abilities of children with CVI, including the specific statement that vision of children with CVI "varied from day to day and even from hour to hour" (Jan, et al., p. 572). Since 1987, medical and educational CVI literature has often quoted this specific statement of visual variability of children with CVI. The description seems to suggest that the enigmatic and erratic vision of children with CVI is internally driven and therefore educational interventions may have limited value in improving the children's visual capabilities.

Recently, Roman-Lantzy (2007) offered an alternative and more hopeful viewpoint. She proposed that children with CVI exhibit inconsistent vision because of changes and variations in external, environmental conditions rather than internal neurological processes. The difference of these two viewpoints is important and accounts for different perspectives regarding the capability of children to *learn* to see. Roman-Lantzy's book guides educators how to evaluate functional vision and construct individualized learning environments to optimize and improve the children's vision capabilities (Roman-Lantzy). Newcombe recently completed a study to validate the concept that children with CVI have relatively stable vision in an identical environment. When children with CVI (N=20) were retested in the same physical setting, by the same person at the same time of day, and with the same materials, test retest reliability was 0.99. Newcombe's study points to the relatively stable vision of children with CVI when environmental variables are held constant (personal communication, February 1, 2009).

Cortical visual pathways are comprised of the dorsal and ventral streams (Stasheff & Barton, 2001). The dorsal stream, located between the occipital lobes, conveys data about the whole scene to the posterior parietal cortex. The posterior parietal lobes function to process a large amount of visual information and give selective attention to different parts of the visual scene. Essentially the brain functions to select relevant information and suppress irrelevant visual information (Das, Bennett, & Dutton, 2007).

Das, et al. (2007) described the complex cognitive visual pathways involved in the visual process of surveying a scene visually, locating and recognizing an object, and choosing a plan of action. Part of the process includes the temporal lobes, which tries to recognize the object from its image libraries. The posterior parietal lobes serve to consider the complete visual scene and interact with the frontal lobes to choose the specific object of interest and plan a visually guided movement. Dutton (2003) stated that given the subconscious nature of our movement in visual space, we do not actually watch where we are going. Visual attention involves multiple parallel and serial processes, and the capacity to move efficiently through the visual world is considered to be subconscious, reflexive and highly accurate (Das, et al.).

Children with dorsal stream dysfunction have difficulty processing complex visual scenes, including seeing things in the distance which involves a wider visual scene. These children may also have difficulty moving through three-dimensional visual space, including problems differentiating floor surfaces, steps, and curbs. Some of the children may have preserved close-up stereopsis (three-dimensional vision) although they cannot accurately negotiate movement in space (Dutton & Jacobsen, 2001). Saidkasimova, et al. (2007) identified seven children demonstrating good visual acuity but a composite of visual deficits common to dorsal stream dysfunction including simultanagnosia, difficulty while navigating crowded visual scenes, decreased visual attention, inaccurate visually guided movement and decreased vision in the lower visual field. Children with dorsal stream dysfunction may also exhibit emotional and behavioral responses including disorientation and frustration. All seven children had identifiable occipito-parietal periventricular white matter abnormalities.

The ventral stream, traveling between the occipital and temporal lobes, is responsible for visual recognition of people, shape and form of objects, route finding, and visual memory (Dutton & Jacobson, 2002). When looking at a face, the image of a face passes along the ventral stream to the temporal lobe where the image is compared with a data bank that stores previously recognized faces. Damage to the temporal area can impair face recognition (prosopagnosia) or understanding of the emotional and linguistic significance of facial expressions (Dutton & Jacobson; Dutton, 2003). There are many levels and differences of visual performance of children with prosopagnosia. For example, some children with prosopagnosia may be able to identify people and photos but they cannot understand symbolic visual information such as line drawings of the face (Morse, 1999). It is important to correctly diagnose impaired face recognition so the child is not misdiagnosed with autism (Hyvärinen, 2005).

Stasheff & Barton (2001) distinguished the visual impairments that occur along the visual pathway. Lesions of the visual pathway up to and including the striate cortex result in defects in the contralateral visual field. These deficits are spatially specific (in terms of visual field) but modality nonspecific. The hierarchy of extrastriate areas often refers to higher-level cognitive visual skills. Lesions occurring beyond the striate cortex impair specific functions of vision but spare visual field and acuity.

The model of two extrastriate visual subsystems includes the ventral pathway involved in object recognition and close up engagement with objects and the dorsal pathway involved in the panorama, including spatial processing, motion perception, stereopsis, and visuospatial attention. Damage often crosses the borders of these two subsystems and as a result, each child with CVI exhibit unique combinations of visual field and perceptual deficits (Stasheff & Barton, 2001). Dorsal and ventral stream damage sometimes can result in visual errors of depth perception and perception of multiple targets, which can be misdiagnosed as visual field impairments (Dutton & Jacobsen, 2002).

Hyvärinen (2004) has taken issue with the terms lower and higher visual functions. She concludes that all visual functions are interconnected and at the same level. For example, although acuity is generally considered a lower visual function, a person requires higher-level function such as intact form perception and visual memory in order to describe accurately what he/she is seeing.

Severity of CVI

Hoyt (2003) compared the visual function and recovery of children with primary visual cortex lesions versus those with periventricular leukomalacia by undertaking a retrospective review of 170 patients seen between 1979 and 1994 at the University of California San Francisco. These children were placed into one of six levels of functional vision, according to their performance on a functional vision examination. Overall, the children with periventricular leukomalacia had poorer outcomes with less spontaneous recovery as compared with the children with pure striate damage.

Oftentimes, children with CVI have brain lesions in both the striate cortex and the white matter pathways, resulting in more complex visual dysfunction. Severity and prognosis of visual function is the result of combined factors of etiology, time of onset, location, extensiveness of brain damage, and associated disabilities (Good, et al., 1994).

When the entire primary visual cortex is damaged, it would seem logical that children would be completely blind. However, secondary to a reflexive visual pathway that includes the superior colliculi, some children continue to have partial visual abilities.

This phenomenon is called *blindsight*. The children are able to discriminate movement and ambulate without bumping into obstacles although they do not appear conscious of their visual ability (Groenveld, 2004; Dutton & Jacobson, 2002; Jan, et al., 1987). Giaschi, et al. (2003) described a 21 year-old boy with complete damage to the striate cortex. Although nearly blind for conscious visual analysis and identification of still objects, he nevertheless could ride a bicycle safely, play video games, and negotiate the environment. Unlike all the other documented cases of children with blindsight who lack conscious awareness of vision, this boy uniquely had some visual awareness as he could describe his environment, although to a limited degree. The authors proposed that the boy's conscious visual perceptions might have resulted from the reorganization of his visual system to compensate for the loss of the striate cortex. Interesting cases such as this are of great importance to researchers and educators as the occurrence of neural reorganization resulting from brain plasticity offers hope of improved vision for children with cortical visual impairment.

A variety of nomenclatures for classifying severity of CVI have been proposed and utilized for the purposes of research and therapeutic/educational intervention. Huoa, et al. (1999) developed a nomenclature for quantifying functional vision in 170 children with CVI. The six levels of vision ranged from level on where a child had only light perception to the sixth level that represented normal vision. Of the 170 children with CVI in their study, the greatest number of children (n=73) displayed very limited vision at level one. Level 2 was the next most common level with 47 children. Of the 96 children who returned to the clinic for follow-up, the average change in vision was 0.9 levels, with

60.4% of the follow-up population exhibiting some improvement in vision, 2.1% exhibiting a visual decline, and 37.5% showing no change. The prognosis for visual recovery was better for the younger children, suggesting visual improvement resulting from neural plasticity may occur more readily during early development. Matsuba and Jan (2006) followed 423 children with CVI and found that 70% had non-ambulatory cerebral palsy, 86.7% had moderate mental retardation or lower, and 14.9% had sensorineural hearing loss. The majority of children showed improvement over time in their visual acuity levels, as measured by Teller Acuity Cards. Matsuba and Jan postulated possible underlying causes for visual improvement, including the incomplete and reversible posterior pathway damage and brain plasticity.

Roman-Lantzy (2007) stressed that CVI is not static; it either improves or declines. She has developed a functional visual assessment that evaluates a child in the presence or absence of ten behavioral characteristics that include color preference, need for movement, visual latency, visual field preferences, difficulties with visual complexity, light-gazing and non-purposeful gaze, difficulty with distance viewing, atypical visual reflexes, difficulty with visual novelty, and absence of visually guided reach. Total scores related to these characteristics place the child into one of ten visual levels (ranges). These ten ranges are grouped into three phases of severity, which guide educational interventions and environmental considerations (Roman-Lantzy, 2007).

Associated Ocular and Neurological Abnormalities

Many children with CVI exhibit concurrent ocular abnormalities. In the 2004 study of 98 children with CVI at the Vanderbuilt Eye Institute, 40% of the children had optic atrophy. Nystagmus was present in 21% of the children (Khetpal & Donahue, 2007). A longitudinal study by Matsuba and Jan (2006) found that 72 of 423 children with CVI had nystagmus. In a study of common ocular features of 30 children with CVI, Jan, et al. (1987) reported that 33 of the children did not have associated ocular pathology and 16 had mild optic nerve atrophy. Children with superior periventricular damage may have bilateral lower visual field impairment (Dutton & Jacobson, 2002). Visual field defects result from lesions in the primary visual cortex (Groenveld, 1994). Dutton and Jacobson stated that various oculomotor disorders such as strabismus, inaccurate fast eye movements (dysmetric saccades), deficient smooth pursuit, and upward deviation of the eyes are common with children with CVI.

Many children with CVI have additional physical and mental disabilities. In a 2004 study of 98 children with CVI at the Vanderbuilt Eye Institute, additional neurological abnormalities included epilepsy (65%) and cerebral palsy (38%; Khetpal & Donahue, 2007). In a study of 2,155 children with visual impairment at the point of entry into early intervention programs, 68% of the children had disabilities in addition to visual impairment (Hatton, et al., 2007). In their study, Jan, et al. (1987) found that all the children had associated neurological deficits and most had multiple disabilities and received complex support services. Matsuba and Jan (2006) determined that 86.7% of a group of 423 children with CVI had moderate mental retardation or lower. Hoyt, R., Burden, Hoyt, C., and Good (1999) reported 75% of the children with CVI had at least one associated neurological abnormality, most commonly seizures (n= 90), followed by cerebral palsy (n= 44). As the corticospinal tract is adjacent to the lateral ventricles, this area of ischemic damage is responsible for the large number of children with concurrent periventricular leukomalacia and cerebral palsy (Brodsky, et al., 2002). In a study of 65 infants with periventricular and intraventricular hemorrhage and leukomalacia, cysts in the periventricular white matter were generally associated with spastic diplegia and poor vision while cysts in the subcortical white matter were associated with CVI and quadriplegia (Eken, de Vries, van der Graaf, Meiners, & Van Nieuwenhuizen, 1995).

Evaluation of CVI

Evaluation procedures to diagnose CVI differ among physicians and researchers. Signorini, Bova, La Piana, Bianchi, and Fazzi (2005) stated that clinical signs and symptoms form the basis of CVI diagnosis. Radiological and electrophysiological studies can support the diagnosis and help determine the sites of the lesion. Signorini, et al. (2005) based CVI diagnosis on both neurobehavorial responses, including direct observations such as light localization and pursuit of a moving object, and indirect observations such as changes in postural reactions and respiratory frequency. Good, et al. (2001) found that clinical examination was usually sufficient to diagnose CVI. They cautioned that poor ocular motor control and sub-clinical seizures could mimic visual behaviors associated with CVI. Snellen eye charts are generally not reliable for children with CVI. A combination of visual function history by the parents and simply playing with the children to observe how effectively they could use their vision was the most effective method of diagnosing CVI (Jan, et al., 1987). Dutton (2005) described a clinical approach to diagnose CVI that included structured history taking and clinical examination, and imaging of the brain when necessary.

Many researchers have described the benefits of various neuroimaging options. Casteels, et al. (1997) recommended a cranial MRI because the anatomic integrity of the optic radiations rather than the visual cortex offered better prognosis. Other imaging techniques include ultrasonography, computed tomography (CT), magnetic resonance imaging (MRI), positron emission tomography (PET) and single photon emission computed tomography (SPECT; Good, et al., 1994). Brodsky, et al. (2002) explained the usefulness of MRI to differentiate gray and white matter and thus distinguish cortical and subcortical retrogeniculate injury. Similarly, Chen, Weinberg, Calano, Simon, and Wagle (1992) compared CT results with the ability of 30 infants with CVI to recognize faces or toys. Object vision developed in 15 of the babies, but CT did not distinguish infants with and without object vision. Chen, et al. concluded that using MRI instead of CT might have revealed white matter abnormalities, which might have better correlated with the child's functional recovery of object vision. Weiss, Kelly, & Phillips (2001) compared 31 visually unresponsive infants with 31 control subjects. They found that all 16 of the babies with developmental delay showed abnormal VEPs and neuroimaging. Results of this study, based on developmental status, responses to visual acuity, VEP, and oculomotor testing differentiated three groups of infants with abnormal visual responses, which included visual inattention, cortical visual impairment, and oculomotor apraxia.

Good, et al. (2001) discussed advantages and disadvantages of various CVI evaluation methods. Forced-choice preferential looking (FPL) tests measure acuity by noting the narrowest grating that attracts the child's visual gaze. However, inattention and head control deficits may decrease reliability of this method. Several types of visual evoked potentials (VEPs) specifically evaluate specific aspects of visual function such as contrast sensitivity and grating acuity. PET scans are not widely used because of requiring a radioactive isotope. Unlike MRI, ultrasound can detect periventricular leukomalacia during the first few days of life. An MRI is useful to illuminate metabolically active areas of the brain, but an alert, immobile and cooperative child is prerequisite (Good, et al., 2001).

Despite increasing sophistication of neuroimaging techniques, even experienced pediatric ophthalmologists find it difficult to make correct diagnosis of CVI. Jan states that previous physicians have incorrectly diagnosed approximately half of the children referred to their Visually Impaired Program. Children with visual disorders are most effectively evaluated and managed by a team of professionals (Jan, 2001). Hyvärinen (1995) conferred that a team of varied professionals could more accurately assess a child's visual ability. Good, et al. (2001), among other researchers, stressed the importance of early and accurate assessment. Watching children interact within their environments allows skilled observers to diagnose higher-level visual deficits. Ahmed and Dutton (1996) argued that although there sometimes was insufficient evidence to substantiate definitive vision impairments, making a probable diagnosis facilitated the implementation of beneficial accommodations and strategies.

Hyvärinen (2004) outlined the complex and multifaceted components of a vision evaluation for children with CVI including administering tests of refractive errors, accommodation, ocular motor functions, refractic errors, saccades, visual field, photophobia, scotomas, visual crowding, contrast sensitivity, and color vision. She additionally recommended tests of motion perception, lengths and orientation of lines, recognition of features and expressions, picture perception and picture comprehension, depth perception, perception of surface qualities, spatial awareness an orientation, eye-hand coordination, simultaneous agnosia, and effects of posture on vision. Hyvärinen further explained that when a child is seeing abnormally, his/her emotional responses, memory, and overall perceptions about the world might be working in very different ways than children who see efficiently. Because of the complexity of vision, children with CVI sometimes require months or years of observation by their parents, teachers, and therapists in order to understand their unique vision. She stressed that a transdisciplinary functional assessment is essential to understand the complexities of children with CVI (Hyvärinen, 2004).

CVI Intervention

Researchers are beginning to understand the physiological mechanisms that may attribute to visual recovery of children with CVI and why most children with CVI improve their vision over time. Damage to the brain structures and pathways are usually incomplete because the normal maturation of the visual system may reveal a higher level of residual visual residual function than initially observed. Additionally, mechanisms of plasticity are important factors in brain recovery (Hoyt, 2002).

Jan and Freeman (1999) described how current understanding of multiple visual pathways in the brain has led to radical changes in the diagnosis of visual and neurological disorders. *Seeing* utilizes dozens of visual pathway and specialized areas of the brain in order to process and analyze the building blocks of vision such as color, shape, size, movement, contrast, and depth. Discoveries about the capability of the brain to adapt and alter visual pathways suggest that improvement of visual function is possible (Edelman, et al., 2006). Subsequent to brain damage, the presence of parallel visual pathways allows alternate areas of the brain to take over receiving visual information (Hyvärinen, 2004).

In 2007, Roman-Lantzy published the first book specific to the assessment and intervention of children with CVI (Roman-Lantzy, 2007). Her seminal book guides the design of activity and environmental adaptations based on the child's specific visual behaviors with these adaptations and activities embedded into all aspects of the child's daily routines. Roman-Lantzy focused on the primacy of parents in the assessment and intervention process. Roman-Lantzy discussed the importance of maximizing the number of opportunities available for the child to engage visually. Rather than challenging children with visual stimuli above their current visual skill level, she recommends keeping visual stimuli precisely at the children's current level of visual interest and capability. By increasing the daily frequency of the child's looking behaviors, the brain has the possibility of making new visual pathways.

With the sudden influx of children diagnosed with CVI, it is essential for educators and therapists working with children with CVI to learn to work effectively with this population. CVI affects every aspect of a child's development and conversely, all areas of a child's development affect their visual abilities. Teachers of the visually impaired (TVI) have a central role in working with children with visual impairments. However, sometimes teachers refer children with relatively good visual acuity but with complex visual perceptual problems to TVIs although other professionals are trained to work with children with these types of learning disabilities (Jan & Freeman, 1998).

Many children with CVI have multiple disabilities, including motor and cognitive delay, difficulties with language and communication, and social skills (Good, et al. 2001). Because of the large percentage of children with CVI with associated cognitive and neurological deficits, Matsuba and Jan (2006) recommended that a multidisciplinary team coordinate assessment and intervention of children with CVI in order to meet their vision and development needs. Edelman, et al. (2006) presented a list of guidelines for quality education for children with CVI. Foremost on the list is careful, reliable, and systematic assessment and instruction by professionals who are trained and qualified to work with children with CVI.

Environmental adaptations and accommodations for children with CVI need to address specific student deficits and should occur across all environments and activities (Roman-Lantzy, 2007). Hyvärinen (2004) recommended that the medical and education team work together. In school, the TVI is instrumental in gathering the clinical findings. For each impaired function, the team needs to determine how it affects communication, mobility, daily living skills and near vision tasks. Dutton (2005) suggested that educators determine visual-perceptual limitations in the three parameters of social interaction, access to information and mobility of the arms and legs. Hyvärinen (2005) recommended the clinical evaluation of oculomotor function in relation to head and body control, quality of the visual image and the use and processing of the image. Many children with CVI, as with children with other severe disabilities, are easily overstimulated in enriched school environments. As a result, these children may be unable to cope effectively in their school setting, resulting in behavior disturbances, including sleep disturbances and physical self-abuse. Although the trend in many public schools is the integration of disabled children into mainstream education, children with CVI require simplified environments.

The literature points to a few specific therapeutic strategies to help diminish CVI characteristics. Good, et al. (2001) recommended strategies of tactile and verbal reinforcement and the ritualization of tasks. Few studies address the efficacy of specific therapy and educational strategies. Cohen-Maitre and Haerich (2005) found that most children with CVI prefer to look at bright colors as compared with gray color and they prefer looking at moving objects as compared with static objects. Cohen-Maitre and Haerich suggested that educators combine visual information with information received from the other senses when teaching children with CVI to learn how to recognize objects.

Good, et al. (2001) noted that there is no precise and proven treatment for children with CVI. The authors stated that the goal of visual rehabilitation is to maximize functional vision in special environments and visual stimulation may help to promote residual functional vision and prevent developmental delay. They recommended simplification of the visual environment and use of high contrast, color, and motion. Edelman, et al. (2006) promoted a family-centered approach to CVI treatment on the basis that parents know their children the best. Importantly, parents have proven to be reliable reporters of their children's visual behaviors (Roman-Lantzy, 2007).

There are differing opinions regarding the efficacy of implementing specific vision stimulation training for children with CVI. Powell (1996) developed a visual training protocol that replicates the developmental stages of normal infant vision, although without consideration of the specific pathophysiology and visual preferences of the children. Hyvärinen (1995) recommended incorporating visual stimulation activities into a broader early intervention program. Sonksen, Petrie, and Drew (1991) compared 58 visually impaired babies, of which half the babies participated in a specific visual program to promote visual development. After 12 months, the babies in the visual program, as compared with the control group, scored higher on nine dependent variables such as visual tracking, near and distant acuity and attention. Limitations of this study were the small sample of nine babies with CVI among the 58 babies in the sample. Additionally, eight of the nine babies with CVI made visual progress, including babies in both the sample and control groups. In another study, 21 children with CVI received an intensive visual stimulation program with multiple daily replications of vision components such as outline perception and ability to see details within a configuration. In the study, 80% of the subjects improved significantly as measured on a seven-point scale of visual development. Unlike other similar CVI research, this study did not correlate the age of the subjects with improvement in visual function. The authors suggested that the stimulation program provide the brain with the opportunity to form appropriate neural connections necessary for visual recovery (Malkowicx, Myers, & Leisman, 2006).

Hyvärinen (2004) advised that visual stimulation combine with stimulation of other senses, unless the child had difficulty simultaneously integrating information from more than one sensory modality. Hyvärinen recommended combining activities to help the child integrate visual clues with other sensory input, such as working on vision in a warm bath or during eating and grooming. Hyvärinen (2005) also recommended neurodevelopmental therapy to improve balance and organize information from the peripheral visual fields, the inner ears, and proprioceptive information. Morse cautions that treatment should be a dynamic process of helping children with CVI find meaning in their visual world rather than a disconnected and linear visual training program (Morse, 1999).

During the 2005 CVI Summit, Spaid, a parent of a child with CVI, offered advice to professionals working with children with CVI. She stated that in order for a child to attend visually, he/she must first be pain-free and emotionally secure. Spaid stressed the importance of weaving elements that are reinforcing and interesting to the child, such as sound, familiar objects, rhythm, song, and movement. Unique in the literature, she recommended silliness as an important quality to forge a relationship with a child with CVI. Spaid suggested that goals be chosen to increase participation in a dynamic environment and build meaningful experiences with caring people (Dennison & Lueck, 2005, p.81-85).

Sonksen, et al. (1991) distinguished passive seeing and active looking as distinct visual processes in babies. They discouraged vision stimulation technique of flashlights in darkened rooms as this type of visual lure only promotes passive firing of cells in the visual pathways and cortex without triggering active looking. Ferell and Muir (1996) have promoted the elimination of visual stimulation training for children with visual impairments. They argued that the research for visual stimulation training was weak, the procedures diminished a child's sense of normalcy, and self-esteem and the training process consumed time better spent in real-life activities.

In a single subject study of a 14 month old boy with CVI, severe developmental delay and physical limitations, Lueck, Dornbusch, and Hart (1999) summarized mixed outcome following a program of incorporating a specially designed environment, visual skills training and visually dependent task training. The authors cautioned future researchers of inherent difficulties when conducting research with the CVI population who often exhibits fluctuating health and performance, slow progress, and the confounding effect of maturity on the visual system. Blanchette (n.d.) studied the visual behavior of three severely disabled students with CVI in her classroom following the implementation of specific environmental modifications. Blanchette took the multidisciplinary approach of integrating therapeutic services into functional routines in class, rather than separating children for vision stimulation. She utilized Roman-Lantzy's *CVI Range* Rating Scale to monitor whether the students' levels of CVI resolved after implementing specific environmental modifications. To facilitate visual recognition, Blanchette simplified the visual environment by making adaptations in terms of color, high contrast, and motion. After 12 weeks, all three children demonstrated gains in their ability to localize, fixate, and track a target.

Mary Morse (1999) has cautioned the practitioner that CVI is a complex disorder. With an estimated 40% to 80% of the brain required to process and understand a visual message, it is important for educators to have broad knowledge about brain function and the outcomes of brain dysfunction. She reminded the practitioner that vision is also a psychological process and a unified understanding of motor, cognitive, emotional and communication issues must stay at the forefront when planning visual services. Emotionally, children will more efficiently use their visual system when they feel confident, motivated, and safe whereas they tend to avoid visual participation when they are feeling overwhelmed, bored, tired, submissive, or stressed (Morse). Hyvärinen (2005) explained that the brain integrates information from all the senses into a holistic experience from which the child learns to understand the visual world. Morse advised that visual skills would best improve when children have opportunities to learn from daily experiences and routines. Linda Burkhart (2003) advised that careful planning and integrated strategies could significantly promote new visual neural pathways as well as improve learning and communication systems.

Several researchers have advised teachers and therapists to try to imagine how the world might look from the view of a child with CVI as a way to increase their sensitivity about children with CVI. For example, Hyvärinen (1995) wondered how the world might look for a person with CVI who could detect lines and shapes but could not recognize them as specific shapes. Lueck (2005, p. 127) stated that while it is possible to imagine the effects of visual impairment due to anterior pathway damage, it is very difficult to imagine the vision of a child with CVI. She recommended that professionals working with children with CVI should be part of the comprehensive assessment of the child so as to acquire a deep, integrated understanding about how a child with CVI constructs his/her world.

Summary of CVI Literature Review

Until recently, sparse information was available to guide educational and medical professionals in the field of CVI (Jan, 2001). With advances in knowledge about brain plasticity and how the brain processes vision, the field of CVI is expanding on all fronts. Most of the brain is intricately involved in interpretation of the visual world. A child's visual skills strongly affect all areas of his/her development and perceptions about the world. Many more children currently are diagnosed with CVI and diagnosis has become more sophisticated and precise in describing a child's visual function.

The medical field has served to provide the constructs of CVI as a complex condition related to all developmental areas and it is now the responsibility of educators to create positive educational outcomes for children with CVI (Edelman, et al., 2006). Indeed, outcomes of recent studies hold promise that children with CVI have the capacity to improve their visual skills. During the past few years, new books have been published to help guide practitioners. Educational and medical professionals working with disabled children need to be well versed in the rapidly growing knowledge about CVI in order to best help the children reach their developmental potential. As new research continues to evaluate efficacy of educational and therapeutic CVI interventions, it is essential that teachers and therapists stay abreast of current information in order to develop successful outcomes for children with CVI. Research indicates that children with CVI learn best when teachers work collaboratively to maximize and integrate their visual interest, learning, and enjoyment in their visual, physical and social environment.

Occupational therapists have an important role within a collaborative IEP team. Occupational therapists, as members of the IEP team of children with CVI have the training and skills to interpret the medical reports of children with CVI, evaluate motor function and state control as well as design interventions incorporating environmental adaptations and activity analysis. Additionally, occupational therapists have the skills to develop an integrated, functional, and motivating curriculum and environment (Baker-Nobles & Rutherford, 1995). It is imperative that occupational therapists have a broad understanding of the complexities of CVI. Langley, a teacher working with children with CVI has promoted the interrelatedness of vision, posture, and sensory postures of children with CVI (Langley, 2005).She has focused many of her intervention ideas in terms of sensory integration and neurodevelopmental therapy. She listed several handling techniques and sensory cues to enhance vision including providing postural proximal stability, aligning the head and neck, facilitating optimal arousal and attention, and eliciting postural adjustments. Langley also recommended that programming emphasize the integration of vision with other sensory modalities and the implementation of meaningful and relevant tasks including communication and social connection (Langley, 2005).

Linking the common threads of current CVI literature supports the development of *A Team Approach to Cortical Visual Impairment Manual*. At the core, the manual is based on two central premises. Firstly, all children with CVI will flourish in a specially designed learning environment with optimal teaching strategies. Secondly, guiding the child with CVI to *learn to see* and *see to learn* will maximize his/her meaningful participation and performance in the school context.

CHAPTER III

METHOD

The process of developing the manual, *A Team Approach to CVI in Schools,* began with an extensive review of current literature. The literature review incorporated topics related to diagnosis, etiology, associated disabilities, and therapeutic and educational approaches for children with CVI. Additional topics that held importance included brain research and physiology related to CVI and longitudinal studies correlating visual outcome with CVI etiologies. The literature review also sought writings that considered the internal visual world of children with CVI and how the children's visual world affected overall development and school participation.

Pubmed, CINAHL, and Sage databases were utilized in searches for medical and educational resources. Articles specific to OT journal were searched in CINAHL. The OT Search database identified CVI articles specific to the American Journal of Occupational Therapy (AJOT). Internet search engines, including Google and Yahoo, were utilized to seek information and websites that focused on childhood blindness, visual deficits, and CVI. The APH-CVI website provided a wealth of current CVI information. Two books recently published about CVI proved invaluable for integrating medical knowledge with educational strategies. Supplementary information about CVI was obtained through personal e-mails with researchers in the field of CVI and blindness. The American Occupational Therapy Association (AOTA) website was an important resource to link current OT practice with the field of pediatric visual impairment. Books focusing on OT theory as well as the *Occupational Therapy Practice Framework: Domain and Process, second edition* situated pediatric CVI within current OT framework and theories.

Secondary to the process of neuroplasticity, medical researchers concur that the visual capability of children with CVI generally improve over time (Huoa, et al., 1999; Matsuba & Jan, 2006; Edmond & Foroozan, 2006). Despite widespread agreement of the positive role of brain plasticity, there was an absence of medical literature advocating specific educational or therapeutic approaches to recover brain function. On a more limited basis, medical CVI experts suggested ideas to improve children's residual vision (Good, et al., 2001). Similarly, in the field of education, prior to the writings of Roman-Lantzy in 2007, educators accepted the notion that children with CVI suffered permanently damaged visual systems.

In 2007, Roman-Lantzy wrote a groundbreaking CVI book, positing that the neurological system underlying the child's vision is in fact predictable (Roman, 2007). Roman-Lantzy proposes that the child's erratic visual abilities result from inconsistent environmental variables. Roman-Lantzy book urges school teams to work to improve children's visual capacity through the development of new visual neural pathways. During the past few years, Roman-Lantzy's optimistic viewpoint has begun to permeate educational CVI resources, including *A Team Approach to CVI in Schools*. For example, the section of the CVI manual, Brain Research Related to CVI, provides an explanation of brain plasticity as the physiological rationale for visual recovery.

A search of occupational therapy journals revealed only two articles related to pediatric CVI. In a 1995 article in AJOT, Hyvärinen, a pediatric ophthalmologist, reviewed types of visual dysfunction, including cortical visual impairment. Hyvärinen advised a team approach to the evaluation and habilitation of children with visual deficits. She concluded that vision affects all aspects of a child's life and intervention needs to focus on improving both the child's vision and his/her general development (Hyvärinen, 1995). The second article, also published in AJOT in 1995 was co-written by Baker-Nobles, an occupational therapist. She also recommends a team approach for program planning and intervention of children with CVI.

Although much educational CVI literature continues to focus exclusively on improving vision, CVI literature is gradually recognizing the broad developmental needs of the child with CV and the need for an integrated, transdisciplinary approach (Hyvärinen, 2004; Matsuba & Jan, 2006; Roman-Lantzy, 2007). From an OT perspective, estrangement from the many aspects of school participation may be considered a central disability of children with CVI. The CVI manual proposed in this scholarly project stresses the importance of evaluating the wide range of deficits, needs, and interests of children with CVI and providing educational interventions to address the child's full participation in school. The CVI manual clarifies that improved vision and overall improved occupational performance interact synergistically to increase the child's overall well-being in school.

Given their medical background and training in adapting activities and environments, occupational therapists are uniquely positioned to understand and work effectively with children with CVI (Baker-Nobles & Rutherford, 1995). The CVI manual deliberately includes minimal OT theory and terminology because the manual aims toward guiding all IEP team members to access knowledge and skills to work effectively with children with CVI. The manual recommends that team members partly blur professional roles in order to engage in common strategies and common routines with the children. Throughout the CVI manual, authorship and recommendations for the IEP team to confer with the occupational therapist highlights the important role of occupational therapy with this pediatric population.

The *Occupational Therapy Practice Framework, Domain, and Process, second Edition (2008)*, with its central theme of engagement in occupation for the promotion of health and participation in life has provided direction in the development of the CVI manual. Children with CVI present with significant and profound limitations in occupational performance in the areas of education, play, leisure, and social participation. As written in the CVI manual section, Collaboration is the Key, occupational therapists have wide range skills to identify the students' strengths, interests and motivations as well as the many barriers that limit the children's participation and engagement in meaningful activities. Occupational therapists are trained to evaluate the transactional relationships of the child's domains, which include activity demands, performance skills, context and environment, performance patterns, client factors and areas of occupation (AOTA, 2008). The occupational therapist is also uniquely skilled to enter co-occupation relationship of play with the child with CVI (AOTA, 2008). Play, the central occupation of childhood (Bundy, 1993; Singer, Golnkoff, & Hirsh-Pasek, 2006) is often severely limited with a child with CVI.

The literature review revealed that to date, there have been no CVI resources which merge CVI background information with interventions that focus on the child's engagement in activities that give him/her meaning, enjoyment, and a sense of well-being. Similarly, there is previously no evidence of CVI literature that aligns teachers/therapists as both agents for the child's growth and development and partners in the child's social communication and social play. By understanding the complex transactional relationships between the child, his/her context and occupational performance, the occupational therapist can help provide team training to develop motivating, meaningful and fun partnerships with children with CVI.

The CMOP (Law, et al., 1997) helped guide the development of the CVI manual. The CMOP promotes client-centered practice and in this spirit, the manual's overarching purpose is to maximize the child's school participation and his/her sense of well being. The CMOP honors spirituality as the core of the child provided a heart of the CVI manual- to honor the child's need for play and fun, social connection, choice making and meaningful occupations. The *Child Likes and Dislikes* worksheet in the Evaluation section of the CVI manual is an example of tapping into the spiritual realm of the child by discovering and promoting his/her interests, motivations, and delights.

In the CMOP, social connections are important components of the spiritual needs of the client. The IEP manual points to the social isolation of children with CVI and seeks avenues for IEP team members to connect with the child at his/her level and interests. In the CMOP, occupational performance problems result from incompatibility between the person and the environment. Children with CVI have severe difficulties to access and make sense of the environment. The CVI manual guides the IEP team in identifying ways to both adapt the environment and support the child to utilize fully the adapted environment. Unique in the literature about CVI, the CVI manual highlights the three key components of environment, child, and activity in order to promote the child's occupational performance. In the CVI manual, setting up optimal environment and activities are essential steps to maximize learning. Respecting the child's interest and developing therapeutic relationships are also crucial to the child's engagement.

The Person-Environment-Occupation Model (PEO; Dunbar, 2007), developed by Law and Dunbar, is informed by the Canadian OT guidelines for client-centered practice. The PEO Model also provides insight and guidance for the formulation of the CVI manual. The PEO model positions occupational performance as the outcome of the transactional relationships between person, occupation, and environment. This model designates the term *fit* to describe optimal occupational performance, which occurs when the three components of person, occupation, and environment fit closely together. Children with CVI and associated disabilities often present with a fragile and tenuous arousal system, visual system, and accessibility to the environment and activities. Through successful school strategies, the child with CVI can experience a better PEO *fit* resulting in increased participation and sense of satisfaction.

After a thorough search of the literature, the CVI manual, *A Team Approach to CVI in Schools* appears to be the first manual to provide an integrated team approach to help maximize the overall participation and learning of a child with CVI. The CVI manual fills a gap by providing an overview of CVI, evaluation, and intervention strategies to advance team expertise and promote children's learning and participation. By sharing the CVI manual on-line with various vision agencies, the manual may serve to build capacity of IEP teams as well as to promote OT's expanding role with children with CVI.

CVI is presently the fastest growing cause of visual impairment in children. The increase of children with CVI entering school districts requires IEP teams to gain expertise about CVI and learn best practices to work with these children. CVI experts agree that a collaborative transdisciplinary team can best serve the complex needs of these children. Written by an occupational therapist, this paper reviews current literature about CVI and provides support for client centered, occupational based education for children with CVI. The literature review points to a shortage of research based information about CVI. Recently, important CVI manuals have been published which offer excellent strategies for improving the vision of children with CVI. *A Team Approach to CVI in Schools* addresses the needs and interests of the *whole* child, by addressing the dynamic relationship between the child, context, occupation, and teacher/therapist in designing effective school programs.

CHAPTER IV

PRODUCT

The purpose of this scholarly project is to develop a CVI manual, *A Team Approach to CVI in Schools*, with the goal of increasing school participation for children with CVI. CVI is defined as diminished visual acuity or unique visual responses resulting from neurological disorders, rather than from ocular disorders (APH-CVI, 2009). CVI is the leading cause of childhood visual impairment in the western world, due to the increasing survival of premature and sick babies secondary to advances in neonatal medical care (Hoyt, 2003; Ketpal & Donahue, 2007). This manual offers current background information about CVI and strategies for the evaluation and educational interventions for students with CVI in order to increase their school participation.

Despite the increasing population of children with CVI entering school systems, there has been a dearth of educational literature available to school professionals who work with the students. Recently, important new school-based literature has been published to help improve the visual capacity of children with CVI, but there is limited literature to guide teams to improve broad school participation and well-being for the children.

Children with CVI, especially those who have concurrent ocular and neurological disabilities require the integrated support of a large group of teachers and specialists to help them access their education. Current medical and educational literature advises a transdisciplinary team to gain knowledge about CVI and collaboratively develop and implement meaningful activities embedded in daily routines for children with CVI (Hyvärinen, 2004; Matsuba & Jan, 2006). Since team members are presently under-trained in the area of CVI, this CVI manual serves to increase collective knowledge, confidence, and skills to work effectively with these students.

Often children with CVI have severe disabilities and limited ability to participate in school activities within the school context. OT supports client-centered and occupation-based practice through supporting the interrelationship and interdependence of the client, context, and occupation. The goal of OT relates closely to the goal of education for children with CVI, which is to improve participation by engaging in meaningful activities of education, work, play, leisure, and social relationships. Current OT theory and practice support the development of the CVI manual, *A Team Approach to CVI in Schools*. Although the CVI manual focuses on the broad learning needs of the whole IEP team, the core values underpinning the manual are congruent with the core values of OT. The Occupational Therapy Practice Framework, the PEO Model, and the CMOP guide the development of the CVI manual. These three models and frameworks support the child's health and well-being through meaningful and client-centered engagement in occupation and emphasize the importance of a therapeutic teaching relationship with the child. Developing social connections and play skills are two central elements of a child's successful participation in life. Many children with CVI are profoundly limited in their access to social and play participation. While addressing the broad needs and school endeavors for children with CVI, the CVI manual focuses on developing meaningful adult-student engagement to promote participation.

The CVI manual is divided into three parts. Section I, Learning about CVI, offers background regarding incidence, causes, characteristic of CVI, and the importance of a knowledgeable school IEP to work collaboratively with the children. Section II, Evaluation of Children with CVI, describes areas of school function for the IEP team to evaluate collaboratively evaluate and includes an evaluation form to facilitate the team evaluation process. The inclusion of a worksheet to explore the child's likes and dislikes supports the development of a meaningful school program that enhances the well-being and satisfaction of the child. Section III, Education of Children with CVI, focuses on educational interventions by addressing the three core factors of child, environment, and activity. The manual highlights the dual, transactional roles of the educator as both the learning guide and the communication and play partner with the child.

The reader will find the manual helpful to understand the background, neurological basis, and the visual life and experiences of the student with CVI. The manual is designed for school educators to gain expertise and confidence to work effectively with the *whole* child within the child's daily school routines and contexts. The CVI manual promotes the ideas that all team members need to work collaboratively and partially cross the usual professional boundaries in order to meet the needs of these complex children.

A TEAM APPROACH TO CORTICAL VISUAL IMPAIRMENT (CVI) IN SCHOOLS

Donna Shaman, OTR/L

May 2009

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SECTION 1

LEARNING ABOUT CVI

INTRODUCTION

The vista is brightening for children with CVI. With promising new educational programs and interventions, the children have new hopes for seeing better, learning, and participating actively in school.

This manual, *A Team Approach to CVI in Schools,* strives to help children with CVI to better understand their visual world and increase their school participation through skillful and collaborative teaching strategies of the Individualized Education Program (IEP). The first section of the CVI manual includes information about brain function, etiology, types, and severity levels of CVI. The second section offers guidance to the IEP team towards evaluating the child's skills, interests and performance, environmental components and school based activities. The third section presents intervention suggestions and strategies to promote student engagement and learning.

CVI broadly affects all aspects of a child's performance, including his/her visual, sensory, motor, cognitive and social function. As a school occupational therapist, the author of this CVI manual believes a student with CVI will improve both his/her vision and learning through active participation and performance in meaningful school occupations. *School occupations* describe the students' daily school activities and routines including academic work, play, activities for daily living, leisure, and social connections. As is true with all students, school based goals for children with CVI should focus on increasing the child's sense of competence, safety, enjoyment, and self-reliance.

Improving a child's functional vision and supporting his/her active school participation will advance the child towards greater potential and development (Dennision & Lueck, 2005).

Cortical visual impairment (CVI) is a neurological disorder resulting from brain damage, which results in abnormal or unique visual responses to people, objects, and the environment. When a child exhibits one or more visual or behavioral characteristics indicating impairment in their visual and/or visual perceptual abilities, a neurologist, ophthalmologist, or other medical specialist may diagnose the child with CVI.

Three Important Educational Beliefs

1. Children with CVI have the capacity to see more effectively and become more active and fulfilled participants in their school environment.
2. Improved vision and school participation is dependent on a carefully designed educational program consisting of enjoyable and simplified activities embedded in familiar routines and specific to each child's unique visual and learning needs.
3. Effective learning requires that well trained team members work collaboratively in order to improve vision and learning for children with CVI.

(Adapted from Edelman, et al., 2006)

ACKNOWLEDGEMENTS AND SUGGESTED READINGS IN CVI

Three excellent CVI resources are recommended for the school IEP team.

During the past few years, amidst rapid advances in brain research, promising educational programs are evolving for children with CVI. New educational strategies have recently become available for professionals working with children with CVI.

1) *Proceedings of the Summit on Cerebral/Cortical Visual Impairment: Education, Family and Medical Perspectives* (edited by Dennison and Lueck, 2005)
   Presents current information about CVI written by leading medical and educational experts in the field. Parents of children with CVI also provide valuable insight.

2) *Cortical Visual Impairment, an Approach to Assessment and Intervention* (by Dr. Christine Roman-Lantzy, 2007)
   A practical guidebook which provides a structured and sequenced approach to evaluate the child, modify the environment and school activities, and structure familiar daily routines to improve the child's functional vision.

3) *http://www.aph.org/cvi/index.html*
   Currently the only on-line CVI website exclusively devoted CVI for educators and families. The website includes current research by CVI experts and provides practical suggestions for structuring a school program for children with CVI. Dr. Roman-Lantzy is the editor of this website.

WHAT IS CVI

CVI is a brain problem, not an eye problem.

When people think of visual problems, they generally think about problems of the eye. However, children with cortical vision generally have normal functioning eyes but they have damage to areas of the brain related to vision. With 40% to 80% of the brain required to process visual images (Morse, 1990), it is common for brain damage to effect vision. Vision loss results from the brain's inability to properly integrate and organize visual information that it receives from the eyes. It is very difficult for normally sighted people to imagine how a child with CVI sees and perceives his/her environment. Yet it is vital for team members of a child with CVI to try to imagine the child's visual world in order to help provide meaning, support and cohesion to the child's visual experiences (Hyvärinen, 2004; Lueck, 2005).

Three exercises to help imagine the visual world of a child with CVI.

Imagine that you are looking at a blackboard full of complicated math equations, much higher than your level of math. You can see all the numbers and symbols, but you cannot understand what you are seeing. Similarly, a child with CVI may see a world full of colors and shapes with perfect acuity, but he/she may not have any idea what he/she is seeing. The child may not make meaning from the visual images and may not know that the colors and shapes are a car, a hat or his/her mother.

Imagine that you are at a sports stadium, packed full of people, and you know that your sister is somewhere in the stadium. You visually search but you cannot see her among the thousands of faces. You can see the thousands of faces, but the visual environment is just too complex for you to locate a specific person. However, if the stadium is suddenly darkened, and a bright light is shined behind your sister, you will be able to readily spot her (Roman-Lantzy, 2007).

Imagine you can easily find the cheese in the crowded fridge but your brother cannot find the same cheese. He is not able to make visual sense of the cluttered refrigerator.

Each child with CVI is unique.

Each child with CVI presents with unique visual characteristics and educational needs, resulting from the many types and locations of brain damage, additional disabilities, as well as variations in personality, temperament, abilities, interests, and experiences. Sometimes CVI is considered a spectrum disorder because there is a wide range of types and levels of severity (Groenveld, 1994). On one end of the continuum, some children exhibit severe CVI impairment with essentially no light perception whereas other children, with mild CVI, exhibit relatively discrete visual perceptual problems, such as the inability to name colors or recognize faces.

TEAM COLLABORATION IS THE KEY

> School activities should be established within the child's familiar routines and environmental settings by all school staff throughout the school day.
>
> (Roman-Lantzy, 2007)

Regardless of the level of CVI severity, visual and visual-perceptual difficulties can result in broad social, emotional, and learning implications. CVI can negatively affect a child's sense of safety, initiation, and engagement in the environment, feelings of competence, satisfaction, and overall development. Children with CVI have unique visual and learning needs and they require specialized education strategies and environmental adaptations. Amidst the newly emerging field of CVI education, there is no set of universal CVI activities recommended for children with CVI. Rather, the IEP team strives to develop an effective, specific, and individualized plan that addresses the child's strengths, weaknesses, and interests in order to improve the child's performance and participation in school. IEP teams need to develop a systematic, integrated, and collaborative educational approach for children with CVI. The effects of CVI are profound, diffuse, interrelated, and variable, even with children who have relatively mild and discrete symptoms. Spatial difficulties, for example, common with most of the children can affect all aspects of development (Groenveld & Jan, 1990). Each child with CVI is unique. Some children with CVI do not see objects that are moving while other children do not notice objects that are still. Some children can only see one special toy. Others get lost in familiar environments or do not recognize people or facial expressions.

> Seeing is a complex psychological process that affects the child's motor, cognitive, emotional and communication functions.
>
> (Morse, 1999)

The school IEP team, working with the parents, needs to administer a broad evaluation of the child's strengths and disabilities, visual and overall function, and level of participation in the school context. The evaluation should focus on the interactions and fit between the individual child, the activity demands, and the environment. Team collaboration is essential to evaluate the child and to develop and execute a program to help the child optimally see, learn, and interact positively with people and the environment. The team needs to develop a unified focus to build the student's sense of familiarity, trust, and confidence by adapting the child's environment, integrating physical and language supports, incorporating motivating activities and establishing common routines and rituals.

Two types of team involvement define and enrich the collaborative process when working with a child with CVI. Each team member contributes her/his professional knowledge, perspective and wisdom to help evaluate the child's skills, deficits, interests and educational needs, develop a meaningful and effective program, and modify the program based on the child's needs. Additionally, each team member relies on the expertise of the team in order to expand his/her individual skills to work with the *whole* child amidst his/her daily routines and activities. Put another way, it is recommended that the child with CVI does not receive isolated occupational therapy, physical therapy, or speech therapy. To promote effective learning, teachers and specialists should cross discipline boundaries to learn mutual strategies and skills to actively engage the child in daily activities and routines that are infused with optimal and familiar visual, language, movement, sensory, and social opportunities.

Team Roles and Areas of Expertise

Parents

- The parents know their child the best.
- The parents are the real experts of their child
- Studies of parents of children with CVI indicate high level of accuracy of parent report regarding child's background, history and performance.

Classroom teacher

- Team leader and coordinator of the IEP team.
- Manager of the child's educational program, integrates child into class milieu.
- Develops and implements class routines and activities to meet IEP goals and objectives.

Vision Teacher (TVI)

- Expertise regarding vision, acuity, ocular-motor function, and visual fields.
- Teaching strategies for visually impaired children.
- Effects of blindness on child development, performance, and classroom learning.

Occupational Therapist

- Maximize child's functional abilities.
- Modify environment and introduce adapted equipment to maximize performance.
- Develop activities to promote school participation and well-being.
- Implement activities to address visual perceptual, movement, position, and sensory systems.

Speech Pathologist

- Interpret the child's understanding, communicative intent and abilities
- Develop language skills to increase academics and social participation
- Help design and implement communication systems.

Orientation and Mobility Specialist

- Facilitate the child's movement in his/her environment
- Establish a familiar, safe, and meaningful environment for the child.
- Incorporate specialized equipment to support mobility, positioning, and function.

Physical Therapist

- Address motor skills and mobility to increase or maintain physical abilities
- Develop strength, balance, coordination, range of motion.
- Incorporate specialized equipment to support mobility and positioning.

Paraprofessionals

- Implement programs and maintain data established by the team.
- Often works the most with students and can offer ideas of successful strategies.

CVI Expert

- Professionals inside or outside the school who have previous experience or expertise with students with CVI
- All 50 states have federally funded projects that provide assistance and training to families, service providers, schools, and agencies involved with visually impaired, deaf, and deaf-blind children, birth through 21.

To locate your state project for children with visual disabilities-

http://nationaldb.org/index.php

BRAIN RESEARCH RELATED TO CVI

> Recent discoveries about the capability of the brain to adapt and alter visual pathways offer new hope of improved visual function of children with CVI.
>
> (Edelman et al., 2006)

Although brain research and physiology of the brain is complex, it is helpful for educators and therapists to understand fundamentals about how the brain functions as related to CVI. Early neurologists thought seeing occurred when the retina transmitted an image to the brain's visual cortex where it was associated with previous visual experiences and then decoded into a visual image (Groenveld, 1994). Neurologists now know that incoming visual information follows a much more complex path. Current understanding of the multiple pathways of the brain has led to radical changes in the diagnosis of visual and neurological disorders (Jan & Freeman, 1999).

Researchers are beginning to understand brain mechanisms that attribute to visual recovery in children with CVI. Multiple visual pathways and structures in the brain are involved in the visual process of seeing. The brain has specialized areas specific for distinct visual functions such as distant vision, color, motion, visually directed movement, and recognition of faces (Hyvärinen, 2005).

Brain plasticity is an important factor in brain recovery and improvement of visual motor performance (Hoyt, 2002). Brain plasticity (neuroplasticity) is the brain's ability, as the result of new experiences and learning, to reroute old neural pathways, create new pathways, and maximize function of non-damaged structures. Because of the parallel visual pathways and more than thirty specialized areas of the cortex that relay and interpret visual information, undamaged parts of the brain can learn to reroute visual information from areas which have been damaged (Hyvärinen, 2005). Additionally, as the child matures, s/he can gain visual skills as intact areas of the brain gain function (Hoyt, 2002). Overall, the prognosis for visual recovery is better for younger children, suggesting that neural plasticity occurs more readily during early development.

From both neurological and education perspectives, brain plasticity is the mechanism for improved vision. Visual function improves by:

......High frequency, repetitive, and consistent visual and visual- motor experiences

.... Embedded in familiar and meaningful routines

................Carefully designed to meet the unique needs of each child

(Edelman, et al., 2006; Lantzy-Roman, 2007)

Because of brain plasticity, even if the entire visual cortex of the brain is damaged, some otherwise blind children can move about in space without bumping into obstacles and they can even pick up objects, although they will not have conscious awareness of seeing or looking. This phenomenon is known as *blindsight* (Groenveld, 1994).

TYPES OF CVI

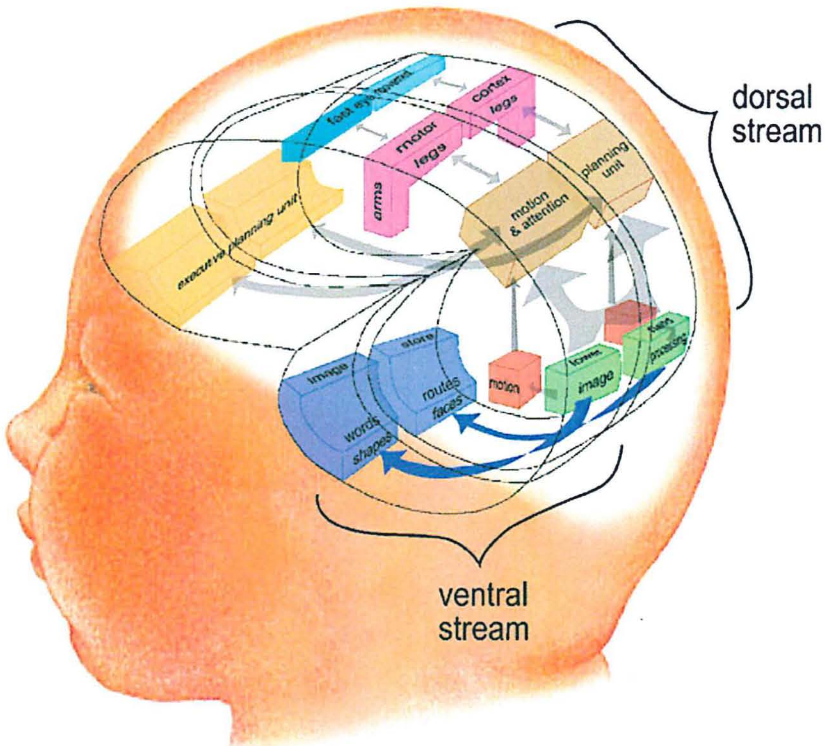
CVI can be viewed as two distinct types. Where the damage occurs along the visual pathways distinguishes lower and higher level cortical visual impairment.

LOWER LEVEL CVI- Damage of the visual pathway up to and including the striate cortex is known as lower level CVI. Lower level CVI affects the child's acuity and understanding of the visual image and ability to see various parts of the visual fields. Lower level CVI vision may vary in severity and type of vision deficit. For examples, the child may only notice bright and nearby objects or he/she may only have visual awareness within certain visual field areas.

HIGHER LEVEL CVI- Higher level cortical impairment (sometimes called cognitive visual impairment) refers to damage occurring beyond the striate cortex. Higher level CVI disrupts specific functions of vision (such as movement awareness, shape, or color recognition) but spares both visual field and visual acuity (Stasheff & Barton, 2001). Although higher-level CVI results in less severe symptoms, the children may present with deficits that severely limit school learning and participation. Children can have damage to both the lower and higher visual levels of CVI.

After visual information is processed in the occipital lobes, the visual data is transferred to other areas of the brain, primarily the parietal lobe and temporal lobes via one of two principal pathways, the dorsal stream, and the ventral stream (Dutton & Jacobson, 2002). Dorsal and ventral streams each serve different visual functions.

Figure I: **Two Pathways-Dorsal Stream and Ventral Stream**



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originally published in Eye (2003) 17, 289-304.

The process of seeing is complex and includes encompassing a visual scene, locating and recognizing parts of the scene, choosing what to look at, and engaging in visually directed body movements (Dutton, 2003). The brain functions subconsciously to efficiently select relevant visual information and suppress irrelevant information. At any given moment, as soon a person looks at a visual vista, the brain makes choices of what components of the vista the brain will visually attend. The person does not notice all parts of the vista because the brain suppresses this information (Das, et al., 2007). Visual attention occurs when multiple areas of the brain act together to select relevant visual information and suppress irrelevant information. Visual attention occurs at multiple stages of visual processing levels. Visual attention, an essential part of efficient vision, often is damaged with children with CVI (Das, et al., 2007).

Dorsal Stream *WHERE* System Processes the 'Whole 3-D Visual Scene including simultaneous and complex scenes. **Dorsal Stream Dysfunction** Difficulty with: • Processing complex visual scenes • Moving through space, especially crowded places and curbs • Visual attention • Finding an object/person from within a group • Simultanagnosia (inability to see multiple objects at the same time • Accurate visual reaching • Accurate movement of the arms and legs in space • Decreased lower field • Emotional and behavioral responses including frustration and disorientation	**Ventral Stream *WHAT* system** Creates a visual library of objects and scenes to compare with visual stimuli. **Visual Stream Dysfunction** Difficulty with: • Visual recognition of people (prosopagnosia) • Understanding emotional significance of facial expressions • Route finding (topographic agnosia) • Various agnosias- recognizing color, shape, length of objects • Visual memory (Dutton, 2003)

INCIDENCE, CAUSES, AND ASSOCIATED DISABILITIES

Cortical visual impairment is the primary cause of visual impairment in children in the western world. With the advancement of medical care in developed countries, more premature and very sick term babies are surviving with neurological deficits including CVI.

(Hoyt, 2003; Ketpal & Donahue, 2007)

The prevalence of children diagnosed with CVI has continued to rise over the past few decades because of increased infant survival rates, advances in understanding of brain function, and improved diagnostic methods (Groenveld, 1994). The actual incidence of CVI is variable in the literature. One in ten visually disabled children in British Columbia had a diagnosis of CVI (Groenveld & Jan, 1990). Hyvärinen states that 20% of visual impairment in children results from CVI (Hyvärinen, 2005). Burt Boyer, Coordinator of Babies Count Project (personal communication, November 5, 2008) reports that initial analysis indicates that 24% have a diagnosis of CVI of the approximate 5,000 visually impaired babies registered during the past seven years with the Babies Count Project.

When initiating an evaluation of a child with suspected CVI, it is important to read the child's birth/medical history to determine the presence or probability of brain damage, which might have caused cortical visual dysfunction.

Causes of CVI include

Meningitis and encephalitis	Hydrocephalus
Hypoxic- ischemic encephalopathy at term	Drugs and Poisons
Brain malformation and syndromes	Near drowning, seizures
Metabolic and neurodegenerative diseases	Neonatal herpes simples
Physical abuse	
	(Good et al., 1994)

In each case listed above, oxygen deprivation in the brain results in damage to cerebral pathways and structures in the brain which process visual information (Roman-Lantzy, 2007). The most prevalent cause of CVI is perinatal hypoxia (too little oxygen to the brain; Hoyt, 2003).

CVI is more commonly associated with other disabilities than most people realize. For example, in a study of a group of children with hydrocephalus (spina bifida), more than half of the children had symptoms of higher level CVI, including problems with shape recognition, simultaneous perception, perception of movement (especially when the child was moving), color, shape, object, and face recognition, and orientation difficulties (Houliston, Taguri, Dutton, Hajivassilou, & Young, 1999).

> The types of cortical visual dysfunction are dependent to a large degree upon the gestational age of the baby at birth, whether the baby is born prematurely or at full term.
>
> (Brodsky, Fray, & Glasier, 2002)

PREMATURE BABIES WITH CVI

Premature infants tend to have damage to the periventricular (area surrounding the ventricles) white matter of the brain. Periventricular leukomalacia (PVL) is the most common cause of brain damage of premature babies and results in a spectrum of associated and often severe disabilities, including learning disabilities, spastic diplegia, limitation of lower visual field, and mental retardation (Dutton & Jacobson, 2002). As many as 70% of children with PVL are diagnosed with ocular vision deficits. Children with PVL often exhibit symptoms of dorsal stream dysfunction (Dutton, 2003). Children with mild PVL tend to demonstrate poor visuospatial skills as compared with relatively better language skills (Jacobson & Dutton, 2000).

FULL TERM BABIES WITH CVI

Full-term infants usually exhibit damage of the cerebral cortex (gray matter) with sparing of the white matter. Visual improvement occurs more frequently with full term babies with CVI, as compared with premature babies. Comparing the two groups, 42% of children with PVL showed improved in vision as compared with 78% of full term children (Hoyt, 2003).

Many children with CVI have additional ocular abnormalities. In one study, nearly 50% had strabismus. Nystagmus is common, especially with premature babies with PVL (Ketpal & Donahue, 2007). Another study found that 65% of the children with CVI had at least on ophthalmologic deficit. Additionally, many children with CVI have oculomotor difficulties such as separating eye and head movements and smoothly tracking objects (Dennision & Lueck, 2007).

Many children with CVI have additional disabilities including:

- Epilepsy (65%)
- Cerebral palsy (38%)
- Non-ambulatory cerebral palsy (74%)
- Moderate mental retardation or lower (87%)
- Sensorineural hearing loss (16%)

(Adapted from Khetpal & Donahue, 2007; Matsuba & Jan, 2006)

CVI CHARACTERISTICS AND LEVEL OF SEVERITY

The visual characteristics and severity of CVI vary widely, so that a child with CVI may have one or many, mild or severe CVI characteristic(s).

Various methods for classifying severity of CVI have been developed for research purposes and therapeutic/educational intervention. This CVI manual will focus on the method of classification and determining CVI severity as described by Dr. Christine Roman-Lantzy. In her book, *Cortical Visual Impairment, An Approach to Assessment and Intervention*, Roman-Lantzy (2007) stresses that CVI is not static, as it either improves or declines. She has developed the *CVI Range*, a functional visual assessment tool developed for educators and therapists. The *CVI Range* evaluates 10 specific behavioral characteristics common to children with CVI. A parent interview specific to the child's vision is included in her book. Parent's responses from the interview are matched to the 10 CVI characteristics.

In a school setting, it is highly recommended that the IEP team collaboratively administer the *CVI Range*. The team's assessment of the presence or absence of each of the 10 CVI characteristics will place the child into one of 10 CVI functional vision levels and three phases of CVI severity. Understanding the three phases of the *CVI Range* will guide the IEP team to formulate classroom intervention plans and environmental adaptations (Roman-Lantzy, 2007). By working together to determine the child's *CVI*

Range, the team will learn more about CVI, establish team interreliability, and better understand the student's unique responses, level of CVI and educational programming needs.

Roman- Lantzy's Three Phases of the *CVI Range*

Phase I- The child is focusing on building visual behaviors, without yet incorporating visually guided reach. These children can only see when there are no visual distractors within a carefully controlled learning environment.

Phase II- The child begins to integrate vision into daily routines, including developing skills of visually guided reach. These children need environmental adaptations but they can visually attend amidst mild, competing visual and auditory stimuli.

Phase III- The child progresses to develop and integrate more typical visual functioning. The child can see within a non-adapted, typical learning home or school environment

(Edelman, 2006; Roman-Lantzy, 2007)

Based on the physician's vision evaluation, it is the role of the IEP team to further access the child's functional vision. Roman-Lantzy's *CVI Range* systematically tracks the 10 behaviors on the *CVI Range*. Following evaluation, Roman-Lantzy recommends specific intervention strategies and environmental adaptations to resolve systematically the child's CVI behaviors (Roman-Lantzy, 2007).

Roman-Lantzy 10 Characteristics/ Symptoms of CVI	
1) Color preference	6) Light-gazing & non-purposeful gaze
2) Need for movement	7) Decreased distance viewing
3) Visual latency	8) Atypical visual reflexes
4) Visual field preferences	9) Decreased visual novelty
5) Decreased visual complexity	10) Decreased visually guided reach
	(Adapted from Roman-Lantzy, 2007)

Hyvärinen (2004) stresses the importance of team members collaboratively evaluating the child for indication of the presence or absence of CVI behaviors. She describes the CVI evaluation as a systematic process initiated by the neurologist, ophthalmologist, and other medical specialists. The child's educational team collaboratively completes the evaluation with the goals of determining how each presenting CVI characteristic affects the child's communication, movement, daily living skills and near vision tasks. A CVI evaluation is a continual process, and it sometimes takes many months to understand the child's vision (Hyvärinen). Although a comprehensive functional vision evaluation will help identify isolated vision issues, it is also important to try to go *inside the heads* of the children with CVI, to understand the *whole* child, in order to help the child become more engaged, curious, and informed.

Working closely with the family, the IEP team considers the integration of the visual, sensory, cognitive, motor, and social needs of the child (Hyvärinen, 2004).

There is a wide variety of CVI symptoms. A child may have one or many of CVI symptoms and the degree of severity for presenting symptom may vary considerably. The first ten symptoms and characteristics listed below are the focus of the 10 CVI behaviors found on the *CVI Range* by Roman-Lantzy. CVI symptoms and behaviors are described by multiple authors in CVI literature and are summarized below.

1) **Color preference**

Many children with CVI have relatively intact color vision, probably because color is represented abundantly in the visual cortex (Groenveld, 1994). Depending on the severity of CVI, a child may only view one single color, a few colors, or only non-patterned colors. Some children may have good color vision but may have difficulty naming the colors because of damage to the visual memory pathway that names objects. It can be useful to determine how close in hue the child is able to discern, as some children can only perceive differences between bright basic colors (Groenveld).

2) **Need for movement**

The visual object may need to be moving, have reflective properties, or the child may need to be moving in order to notice the object. Some children may see better when they are walking or driving in a car. Some children have difficulties seeing objects that move, although this condition is less common. These children may prefer looking at still views on the television, such as watching the weatherperson (McKillop, et al., 2006). Difficulties with motion perception may result in difficulties with sign language, lip-reading, understanding facial expressions, and safe mobility in traffic.

3) **Visual latency**

There may be a lag time before the child responds to a visual object. Sometimes the latency is quite long, so parents and staff need to wait quietly and patiently while the child slowly processes the incoming visual information.

4) **Visual field preference**

The child may show a preference for viewing objects in certain parts of their visual field. Visual field preference is very hard to measure in children with additional visual deficits. Sometimes the visual field loss is in the center, so that the child uses the surrounding areas and he/she appears to be looking past the object.

5) **Difficulties with visual complexity**

The child only looks at simple objects against simple backgrounds. The child may have difficulties with *crowding* and can see only an isolated object if it is positioned at some minimum distance from another object.

6) **Light gazing and non-purposeful gaze**

The child may be attracted visually to bright lights. Sometimes the child locks his/her gaze on the light source.

7) **Difficulty with distance viewing**

The child may only attend in the near space. This occurs not because of an acuity problem, but because the child is trying to suppress background information. The visual vista may be too much complex with closely placed and simultaneous objects.

8) **Atypical visual reflexes**

The child sometimes does not blink when you approach your hands to his/her eyes.

9) **Difficulty with visual novelty**

The child may only look at familiar or favorite objects, with little regard to novel objects. The child presents with overall decreased visual curiosity.

10) **Decreased visual guided reach**

The child does not coordinate looking and reaching so that he/she may look away during the act of reaching. The child may exhibit decreased accurate reaching. Sometimes the child performs reaching activities better with his/her eyes closed.

11) **Seeing is tiring**

Spontaneous visual attention and interest occurs briefly for children with CVI. The children need to analyze visual information in small units and require a longer time to process information (Groenveld & Jan, 1990). Children with CVI need environmental accommodations to maximize the effectiveness of their vision, increase visual attention, and preserve energy.

12) Eyes appear normal

Many children with CVI have eyes that appear normal to the observer, although some children have additional ocular abnormalities.

13) Photophobia

The child may react negatively to lights. Special filter or absorption lenses (sunglasses) can be helpful to the child and should be part of the child's clinical evaluation (Hyvärinen, 2004).

Some children exhibit simultaneous photophobia and light gazing. Sometimes children are drawn to looking at lights, even though it upsets them (Jan et al., 1993).

14) Contrast sensitivity

Contrast sensitivity is the ability to see differences in the luminance of adjacent surfaces of objects or space. Visual information at low contrast is important in social situations, for example, the ability to see changing facial expressions (which requires both visual skills of low contrast and motion).

15) Abnormal eye and head movements and position (Oculomotor deficits)

Many children have stereotypical head position or tilt, as they try to observe objects peripherally or to accommodate a field loss. Some children have abnormal oculomotor function including impaired ocular pursuit and ability to fixate their gaze. Adequate oculomotor function includes the ability of the eyes to align properly and exhibit smooth eye pursuits, saccades (moving the eye from point A to point B in order to track an object), and convergence. Abnormal muscle tone affects oculomotor function, and movements of the eyes can affect muscle tone. Oculomotor function is supported by feedback of the vestibular system and proprioceptors of eye muscles. The occupational therapist and vision teacher should collaborate to evaluate the child's eye movements and oculomotor function.

16) Difficulty with multiple sensory inputs

Some children cannot effectively use their vision at the same time as they touch or listen. For example, the child may stop using his/her vision when someone speaks or when the bell rings. The child may close his/her eyes when listening.

17) Depth perception

Many children with CVI have difficulty with depth perception (three-dimensional sizing, distancing, and positioning in space). Depth perception requires lower-level stereovision (both eyes working together) as well as integration of higher-level visual skills, such as understanding the relative movement of an object at different distances as a person moves through space. Depth perception also requires that the child understands shadows, partial presentation of a known object when part of the object is hidden, and the relative size of known objects.

18) **Perception of surface qualities**

This includes various problems including the child not remembering or understanding landmarks, qualities of different surfaces, spatial relationships of objects in the room, or his/her overall relationship to the environment.

19) **Visual agnosias**

Children with damage to the dorsal stream may experience various types of visual agnosia (decreased ability to visually recognize or identify objects or people). There are a many types of agnosias including the inability to focus on more than on object, problems with orientation, depth perception, and perceiving moving targets (Good, 2001).

One specific type of agnosia, called *prosopagnosia*, is the understanding of human faces. Type and severity of prosopagnosia is variable. Some severely involved children cannot recognize their parent's faces. Other children do not understand facial expressions, photographs, or line drawings of people. There are varying causes of prosopagnosia. Face recognition may be impaired because of decreased contrast sensitivity or because face recognition is impaired at a cortical level.

Faces can be confusing as they change with different expressions, hairstyle, and make-up. Faces are complicated by multi-sensory visual, auditory, and olfactory inputs. In the educational setting, it is important to evaluate whether the child can understand pictures and photos of people and the level of complexity that the child can understand. For example, an otherwise high-functioning child may lack the cortical visual skills to create a whole picture from the many parts in a photo. It is important that prosopagnosia be properly diagnosed so that children are not diagnosed as having autism (Morse, 2005).

20) Perception of length and orientation of lines

There are specific parts of the brain that perceive length and orientation of lines. Specific areas of the brain are responsible to adjust a person's reach and grasp and to respond accurately to information of the length and orientation of an object. For example, when trying to place a dowel into a hole in a container, first the brain needs to determine which way the hole is oriented and another part of the brain orients the hand to make adjustments so the dowel will fit correctly into the hole (Hyvärinen, 2004).

21) Spatial awareness and orientation in space

Proprioceptive feedback from the neck and extraoccular muscles locates a visual map that matches the environmental location with the amount of head and eye rotation relative to the child's body. Children with PVL may experience severe challenges moving through three-dimensional visual space (Dutton, 2003).

22) Social skills

CVI is socially debilitating in both mildly and severely affected children. Sometimes a child is labeled as naughty because professionals think the child is deliberately refusing to look at a person or object. Children with CVI may have difficulties interpreting facial expressions, learning how to communicate effectively, and making friends (McKillop, 2006).

(When not otherwise specified, CVI behavioral characteristics are compiled from multiple sources of CVI experts in the field of CVI and visual impairment including: Groenveld, 1994; Roman-Lantzy, 2007; Hyvärinen, 2004: Good et al., 2001; McKillop, 2006.)

SECTION 2

EVALUATION OF CHILDREN WITH CVI

FUNCTIONAL EVALUATION OF CVI

> "A transdisciplinary functional assessment is essential to understand the complexities of these children."
>
> (Hyvärinen, 2004)

Careful, reliable, and inclusive assessment is the basis for effective educational programming for a child with CVI (Hyvärinen, 2001; Edelman, et al., 2006). Physicians make the medical diagnosis of CVI based on clinical signs and symptoms, sometimes supporting their diagnosis with additional radiological and electrophysiological studies, such as CT and MRI. In general, children with CVI cannot be tested reliably with Snellen eye charts. Dr. Jan has written extensively about CVI and he is probably the most renowned physician and researcher of CVI. Dr. Jan recommends that a combination of visual history by parents and simply playing with a child to see how well he/she use their vision as the most effective medical method of diagnosing CVI. At the same time, Jan stresses the difficulty of diagnosing CVI and he notes that about half of the children referred to his vision clinic in British Columbia have been previously misdiagnosed (Jan, et al., 1987).

When a child sees abnormally, his/her overall perceptions about the world, emotional relationships and memory may be working in very different ways than a child who is seeing efficiently. Children with CVI can be very difficult to evaluate and sometimes the children require months of observation by their parents, teachers, and therapists in order to understand their vision (Hyvärinen, 2001).

Despite new understanding about the brain's complex and critical role in vision, there continue to be many barriers for children with CVI to receive correct diagnosis and appropriate educational services. Many ophthalmologists have not received adequate training in CVI so that children are often undiagnosed or misdiagnosed (Dennison & Lueck, 2005). National and international visual impairment classification systems have not updated their classifications beyond the antiquated visual categories of visual acuity and visual fields, so that children with CVI, especially those with higher level CVI, are often excluded from programs available for children with visual problems (Edelman, et al., 2006). Lack of agreement in the medical community about levels and types of CVI further complicates proper diagnosis of CVI (Roman, 2007). Finally, parents may not have the financial means to have his/her child evaluated by medical specialists in order to diagnose CVI.

CVI is a medical diagnosis, and as such, a physician must make the diagnosis of CVI. Unfortunately, given the many barriers to a proper diagnosis of CVI, many children with signs and symptoms of CVI are not receiving necessary services.

Strategies for working with children with CVI, such as using proper lighting, developing routines, allowing longer response time and simplifying the environment are beneficial for a variety of students without a formal diagnosis of CVI.

Consider that best practices in special education classrooms regularly recommend integrating a wide range of adaptations, such as visual supports and adaptive positioning, based on the functional needs of each student, rather than whether or not he/she has a specific diagnosis such as autism or motor dysfunction. IEP teams similarly need to support the needs of children with symptoms of CVI, with or without a medical diagnosis. The classroom teacher should work collaboratively with the TVI, occupational therapist and other school staff to evaluate the functional vision and perceptual-visual-motor skills of the child, in order to develop an appropriate school program. It is very important to include parents in the evaluation process because they best understand their child's vision.

The CVI Functional Evaluation should include:

- Review of medical history, health, and development of the child, current medical reports including ophthalmology.
- Interview the parents. Roman-Lantzy includes an excellent parent questionnaire in her book. She correlates the parents' responses with the ten behavioral characteristics from the *CVI Range*. It is also valuable to interview the parents and IEP team to determine the *occupational profile* of the child, that is, the child's history of activities, involvement in various contexts, interests, patterns of daily living, values, wants, interests, and needs (AJOT, 2008).
- Direct evaluation of CVI characteristics, visual performance, relation between motor function and vision, and overall school participation in specific school environments.

The *Evaluation of Student with CVI* worksheet (see page 81) can be used to facilitate the IEP team CVI evaluation. Because many children with CVI have a narrow range of activities and situations that they enjoy, the IEP team should collaboratively fill in the *Likes and Dislikes Chart* (92). The *Likes and Dislikes Chart* will help the IEP team develop motivating student activities, follow the child's interests, and monitor the child's expansion of likes and interests over time.

Evaluation of Student with CVI

Name________________________________ DOB _____ Age_____

Grade _____ School _______________________ Date of Evaluation _________

Student Information
Team Members contributing to the evaluation

____

Current Services the child receives: ☐ Speech/language ☐ Itinerant vision ☐ OT ☐ PT ☐ Sped. Ed ☐ Other ______________

Communication System(s): ☐ Oral ☐ Sign Language ☐ Visual Symbols ☐ Gestures ☐ Facial Expressions ☐ Other ____________________________

ELL (home language) _______________________

Medical Information
Birth history/ gestational age/ birth complications:

____

☐ Seizures ☐ Medications ☐ Physical disabilities ________________________

☐ Hearing __________ ☐ Oral intake precautions ________________________

General health: ____

School Attendance: ☐ Good ☐ Fair ☐ Sporadic ___________

Assistive Devices: ☐ Wheelchair ☐ Walker ☐ Stander ☐ Other

____

Mobility/ Positioning: ☐ Run ☐ Walk ☐ Crawl ☐ Tall Kneel ☐ Sit ☐ Other

Effect of movement on vision____

Effect of positioning on vision____

Vision: Ophthalmology results /medical diagnosis of CVI______________________

Educational functional vision _____________________________________

Summary of visual skills ____

____

☐ Roman-Lantzy *CVI Range* ____

Parent Interview

☐ Health and development, birth history_________________________________

☐ Roman-Lantzy Parent Interview competed

Effects of Environment, Types of visual target and location of best vision, description of reach, eye-hand coordination ___________________________

Oculomotor Skills/Deficits ____

____

☐ Higher-level CVI deficits ______________________________________

☐ Recognize people, photographs

☐ Recognizes shapes and objects

☐ Name and match colors

☐ Find route in house and other places

☐ Reach and grasp accurately

☐ Distinguish a step and a line

☐ See moving objects when the child is still and moving

☐ Find objects on a patterned surface or in complex pictures

☐ Walk around obstacles or through doorways

☐ Regards food on all sections of the plate

☐ **Occupational Profile** – Contributed by ☐ Parents ☐ Other ____________________

What does the child do at home/ at school to participate or occupy him/her?

____

In the classroom ____

On the playground ____

When left alone ____

With other children ____

With adults ____

How does the child take care of himself/herself?

Dressing ____

Eating/drinking ____

Toileting ____

Washing ____

Describe the child's performance in the school activities:

Leisure ____

Work/ school jobs ____

Academics ____

Fine Motor ____

Gross Motor ____

Language ____

Social participation ____

Describe his/her temperament ____

Describe his/her memory ____

What are his/her strengths?____

What makes him/her laugh? ____

In what type of environment does the child show her highest visual skills?

____

In what type of environment does he/she seem the least engaged/most stressed?

____

What environmental modifications alter the child's performance?

____

Describe the child's responses to sensory input including: movement, sound, oral/eating, touch, proprioception, vision, multiple inputs? ______________________

____

Describe the child's sensory seeking and sensory avoiding behaviors

____

Describe the child's self-regulation and modulation strategies?

____

What does the child do to get attention?__________________________

How does he/she communicate his/her wants? ______________________

With which adults does the child get along best? Why? _____________

What best holds the child's interest ____________________________

____

What has the been the child's biggest accomplishments during the past year____

Comments:

Plan:

CVI Program Planning

CHILD LIKES and DISLIKES

Name_________________________________ DOB ______ Age______ Grade ___
School __________________________ Date ______

Team Members contributing to the Child Likes and Dislikes chart.

____

From choices in left hand column, **What the Child Likes** and **What the Child Dislikes:**

Categories of Likes/Dislikes	What the Child Likes	What the Child Dislikes
Foods/Drinks		
Sensory		
Vibration		
Swinging		
Massage/ deep pressure		
Tickle		
Movement		
Types		
Speed		
Sounds		
Verbal		
Talking		
Singing		
Music		
Quiet		
Positions		
Sit		
Stand		
Lying Down		
Positioning equipment		

Likes and Dislikes- cont. **Vision** Colors Complexity Distance of objects **Environment** Lighting Locations in class/outside Warmth/ Cold Proximity to Students/ Staff **Activities of Daily Living** Hair brushing Dressing/ Types of clothes Eating/ Drinking Lotions **Social** Favorite children Favorite staff Types of games Joking/ Silliness **Play/ Work** Tactile play Physical Play Playground Social play Imaginative play Constructive play		

Likes and Dislikes-cont. **Play- continued** Solitary play Toy Types Insertion Tasks Matching Tasks **Technology**		

Comments:

SECTION 3

EDUCATION OF CHILDREN WITH CVI

EDUCATION OF CHILDREN WITH CVI

> Vision has a vast and profound influence on all aspects of learning and school participation.

Vision is largely important in the development of eye-hand coordination, visual-oral coordination, visual-object recognition and perception, visual-motor coordination and all academic learning. Vision affects the sense of distance, shape, color, and social interactions. Vision triggers head righting (keeping the head in midline) and underlies a sense of orientation in space (Gentile, 2005).

CVI, whether mild or severe, can negatively affect multiple functions of performance and learning, and can be emotionally challenging to a child's sense of safety and organization. Educational goals need to address the complex and diverse learning needs and the broad educational goals of children with CVI.

Following the functional evaluation to determine the characteristics and symptoms exhibited by the child, the team needs to develop interventions and accommodations to minimize these deficits (Roman-Lantzy, 2007). Morse (1990) suggests that the visual withdrawal behavior observed in many children with CVI may result from their defense against real or imagined threats caused by an overload of sensory information that the brain is not able to organize. One educational goal for the child with CVI needs to be helping the child cope with stress by carefully controlling and adapting the environment (Morse).

Five *Big Ideas* for Working with Children with CVI

1. Understand and be sensitive to the child's visual world.
2. Develop familiar routines and activities.
3. Offer visual stimuli *at* (but not above) the child's level.
4. Approach the child gently, with respect and humor
5. There is no universal CVI program- Each child is unique.

(Adapted from Roman-Lantzy, 2007)

1. Understand and be sensitive to the child's visual world.

The visual world may be very different for a child with CVI. Although it is impossible to understand fully the experience of CVI, it is important for teachers and therapists to gain sensitivity into the visual world of a child with CVI. How might the child might be seeing, feeling, and reacting to his/her environment (Hyvärinen, 2004)? Visually and multiply handicapped children have skewed visual perceptions, decreased experience in using their other sensory systems to extract knowledge, and difficulty confirming and associating their experiences (Morse, 1990). Morse recommends that program planning consider the child's internal physiological and psychological needs, by creating a learning environment that offers organized patterns. Teachers and therapists can help the child build behavioral organization and homeostasis by controlling the type, intensity, and duration of sensory information in order to prevent overloading and damage to homeostasis (Morse).

2. Develop familiar routines and activities.

Activities with children with CVI need to be familiar, repetitive, embedded in routines and function, have a distinct beginning and end, and be of shortened duration. Vision is tiring for children with CVI. Because the development of new brain pathways and synapses occur through the act of looking, interventions must encourage the child to look as much as possible, throughout the day, during all activities in his/her daily life. The learning environment must be set up to facilitate a child's ability and motivation to look (Roman-Lantzy, 2007).

3. Offer visual stimuli at (but not above) the child's level.

Children with CVI lack visual curiosity and seek visual familiarity. Unlike children with normal cortical vision, children with CVI do not get bored of their limited visual repertoire. Present visual stimuli at the child's current level of vision skills, not at a more advanced level. The result of children with CVI looking repetitively at objects within his/her present capability is the building of new brain synapses, through the process of brain plasticity. The child needs appropriate visual stimuli to stimulate him/her to look (Roman-Lantzy, 2007).

Children with CVI will only look at things that they CAN look at. By gaining new brain synapses, the child will resolve specific CVI characteristics and improve visual skills (Roman-Lantzy, 2007). For example, a child might only be interested at looking at a red teddy bear and will not look at other colors or other objects. In this case, the teacher/ therapist should present the red teddy bear for the child to look at for as long a time as necessary. Gradually over time, offer a subtle visual change, such as substituting a red stuffed dog for the red teddy bear. However, if the child is not interested and does not visually regard the new object, return to the teddy bear for additional days or weeks. Later, try again to make an acceptable small change, such as again presenting a purple stuffed dog or another red stuffed animal (Roman-Lantzy). In choosing the child's visual targets and activities, it is important to consider the child's present strategies to process visual information, preferences of novel and familiar experiences, and sensory systems which are most effective (Morse, 1990).

4. Approach the child with sensitivity, respect, and humor.

There is a strong emotional component for children with CVI. The visual world may be inconsistent, confusing, and chaotic. Reaching out and touching objects may be uncomfortable or frightening for the child. Especially when the visual environment and sensory-motor demands overwhelm and deregulate their equilibrium, the child may have difficulties with basic self-regulation and rythmicity, and have difficulties maintaining a quiet-alert state necessary for learning. It is essential that teachers approach the child with sensitivity and respect, offering supportive and safe relationships and experiences.

It is important to weave elements into the child's program that are reinforcing and interesting to him/her such as sound, familiar objects, rhythm and song, and movement. Developing significant relationships is the essence of working with children with CVI. Spaid, a parent of a child with CVI, describes the important human quality of *emotional safety*, i.e. being an advocate for the child's emotional needs. In order for a child to attend visually, the child must first be pain-free and emotionally secure. It is important to weave elements that are reinforcing and interesting to the child, such as sound, familiar objects, rhythm, song, and movement. Silliness is recommended as an important quality to forge a relationship with a child with CVI. Goals be chosen for the child so he/she participates in a dynamic environment and builds meaningful experiences with caring people (Dennison & Lueck, 2005, p.81-85).

5. There is no universal CVI program. Each child is unique.

There is no step-by-step or universal CVI method, but there are common stepping-stones that underlie CVI program development. The three new CVI resources (see page 42) point to the emergence of a methodology that carefully analyzes the child's unique CVI characteristics and systematically designs programs to resolve each of the CVI characteristics. Rather than consider CVI education a special program or therapy, Roman-Lantzy (2007) recommends overlaying CVI modifications and accommodations onto the child's daily routines and classroom activities. Each CVI program must meet the child's unique visual functioning and his/her needs for safety, autonomy, improved vision, task performance, social engagement, autonomy, and fun.

In the school setting, remember that the parent knows the child best and they are usually accurate in describing his/her child. Interviewing the parents reveal critical information about the child's skills and interests. When possible, include home visits to help guide and support families, learn about the child's life at home, and to help the parents develop effective functional routines and activities.

After initially developing and implementing a school program, frequently utilize Roman-Lantzy's *CVI Range*, the IEP, data collection, and skilled observations to direct and update the child's program. Stay current on the child's new interests, likes and dislikes, health, visual skills, overall participation and enjoyment of the school program. Review the child's visual skills and overall performance in the critical areas of communication, movement, daily living skills and near vision tasks (Hyvärinen, 2004). After each session, think about what the child learned, what motivated the child and what went well. Observe and learn how other members of the team engage and work with the child in order to deepen skills and to provide consistency of environment, activities, language, and interaction.

The child's school performance and school participation result from the interaction and *fit* of four critical influences- child, environment, occupation/ activity and teacher/therapist. The CVI manual organizes the list of intervention suggestions into these four factors. Note that many of the suggestions overlap and can fit into more than one category.

1. **Child**- Addresses the child's physical state, motivation, and interests.
2. **Environment-** Promotes vision and the child's positive interactions with his/her surroundings.
3. **Occupation/Activity**- Suggests individual and group activities.
4. **Teacher/ Therapist**- Refines teaching style to develop authentic and positive relationships with the child.

CVI Suggestions Related to the CHILD

- **Behavioral State**
- **Reduce Fatigue**
- **Maximize Visual Attention**
- **Positioning and Movement**
- **Hearing and Sound**

Behavioral State

Behavioral state refers to a child's ability to organize and adapt to his/her external environment. Infants and children with brain damage sometimes have difficulty regulating and maintaining behavioral states and they may fluctuate rapidly through behavioral states (examples: quiet alert, drowsy, crying). The quiet/alert state is the optimal *ready to learn* behavioral state.

Some children have difficulty transitioning out of a crying and upset behavioral state or a dull/shutdown behavioral state. Behavioral states are influenced by intrinsic factors such as hunger, seizures, and general health as well as extrinsic factors such as noise, touch, temperature, and visual input. Vision also plays a big part in establishing biological rhythms. Sleep disorders are relatively common in children with visual impairment (Groenveld, 1994). In an over-stimulating visual environment, the child may become overwhelmed and shutdown by avoiding vision, using vision non-purposefully, closing eyes, sleeping or becoming upset and crying (Baker-Nobles, 1996).

Neurologically, the child's level of arousal and behavioral state is interrelated with motivation, anticipation, and sensory-motor functioning (Morse, 1999). It is important to carefully watch the child's behavioral cues to determine the child's level of alertness, responsiveness, or avoidance as the child learns to gain some sense of control of his/her modified environment. As the behavioral state stabilizes, the child is better available and ready to learn (Baker-Nobles, 1996).

Reduce Fatigue

Maintain short learning and interactive learning sessions. Do not wait for the child to look fatigued before you end the session. Offer adequate pauses for the child to process sensory input and information. Keep requests clear and concise, so the child does not tire or stress as the result of confusion. Understand the environmental and learning demands of the situation relative to the child's abilities and physical state.

Simplify every aspect of the environment and learning situation and avoid extraneous visual and auditory clutter. Give the child the opportunity to sometimes *just look*, without games and social interactions (Roman-Lantzy, 2007). Provide good physical support and positioning so the child does not fatigue from working hard to maintain upright posture. Carefully add new components to the program, such as visual novelty, within the context of familiar social interactions to build a sense of safety and security (Morse, 1990). It is important to remember that many children take a surprisingly long time to process incoming information, organize, and execute a response. Be systematic as to the goals of the session so that each activity strategically and effectively moves the child toward his/her goals.

Maximize Visual Attention

The same parts of the brain involved with receiving visual stimuli are involved with visual attention. The reticular activating system is the alerting system of the brain, which determines which parts of the visual world the child will notice. Visual attention to the environment requires sufficient regulation of behavioral state of arousal and organization in order to respond selectively and reliably to incoming sensory stimuli (Morse, 1990). People, objects, and activities chosen for the child should be intrinsically motivating and rewarding. The child's environment should be modified to reduce and promote behavioral organization (Morse).

Positioning and Movement

Proper positioning and active movement are essential to increase the child's participation in the environment. Children with both CVI and additional motor deficits expend disproportionate effort on head and trunk control, which can result in decreased visual abilities (Gentile, 2002). Many children with decreased trunk or head control require special positioning support so they do not *use up* their limited focus and energy toward maintaining a safe and upright position. Because of neurological connections between the child's body position, movements, and vision, appropriate and varied movement experiences are essential components to optimizing visual capacity (Baker-Nobles, 1995).

Optimal vision requires the integration of visual, auditory, and vestibular information. From a neurological perspective, specific pathways in the brain integrate postural skills with visual information. Dorsal stream pathways help the child orient his/her body movements in space. Components of functional vision, such as the ability to maintain gaze while moving is required for spatiotemporal orientation (the ability of a person to orient in both space and time). Spatiotemporal orientation form the foundation of all aspects of daily life, such as using escalators, stepping up a curb, knowing routes in school, going to the right class on time, and catching a ball (Gentile, 2002)

For children with very severe disabilities, movement itself may be the most meaningful and pleasurable mode of the child's participation and may be central to his/her learning and participation. Many children with CVI see better when the visual target is moving or the child is moving. Movement can be the centerpiece of a social interaction, including actions of rocking, swinging, and bumping into soft surfaces. Many children with cerebral palsy enjoy when adults vigorously drum their arms reciprocally. The teacher/therapist firmly holds the child arms, above the elbows, and rhythmically drums the child's hands against a therapy ball or other surface.

The occupational therapist is trained to guide the team in developing a variety of movement experiences for the student. As with all aspects of learning for a child with CVI, all team members should integrate optimal movement and positioning into all aspects of the child's daily schedule.

Hearing and Sound

Children with CVI often choose to relate auditorally with their environment as sound may be organizing and reinforcing to the child (Burkhart, 2003). Sound and talking may help the child understand visual information and may reinforce the difficult task of looking. For example, the computer screen with specific can encourage vision. After the child looks at the screen, the sound can be activated (Burkhart, n.d.).

Some children with CVI become overwhelmed when trying to use their vision simultaneously with other senses. Depending on the severity of the CVI, it may be beneficial to offer verbal directions and reinforcement separately from when the child is actively looking or reaching. Many children with CVI love sounds and talk, and auditory input can be valuable to motivate the child, help him/her understand visual stimuli or to reward the child for using his/her vision (Burkhart, 2003). It is sometimes helpful before expecting the child to look or reach to first tell the child what to expect, what object he/she will touch, or where the object is located (Weinstein, 2000).

CVI Suggestions Related to the ENVIRONMENT

- **Simplify the Environment**
- **Adjust Lighting**

Simplify the Environment

Simplify and modify the environment and develop visual activities at the child's current level. This is central to the child's educational program to resolve CVI. The visual program should gear to the specific functional visual deficits/ characteristics that the child has not yet acquired or integrated into his/her vision, according to the team's functional visual evaluation of the child. Administer the *CVI Range* to help adapt the child's visual and learning program (Roman-Lantzy, 2007). Try to decrease competing sounds in the child's environment to help simplify the environment.

Many children with CVI cannot look as they reach. Instead, they typically look briefly at the target and then look away as they reach, resulting in limited visual motor coordination. Brightly colored toys or neon gloves or mittens may help facilitate visual hand gaze (Greeley, 1997). Sometimes children with CVI reach for an object with their heads, instead of their hands. Reaching with their heads to touch or activate a toy offers components of spatial and cognitive learning and can be encouraged (Greeley).

Remember to build repetition and familiarity by using the same materials, the same activities and language, and in the same learning environment. Slowly and gradually, add a novel component to the familiar set-up, and backtrack to familiarity, if the child does not respond positively or does not visually attend.

Lighting

Usually, it is best to position lighting behind the child in order to illuminate the target object. It is beneficial if the room is well lit with natural lighting, although sometimes the child responds better in a dim room with a spotlight on the target object. Sometimes the use of a light table increases visual focus and interest. However, some children with CVI are easily overstimulated. These children will visually withdraw from a light table, because their brain is not able to inhibit or screen intense or non-essential information. Sometimes the child initially shows good attention to a light table, but later shows signs of discomfort or withdrawal (Wright, n.d.). It is also important to remember that the child with CVI may have photophobia (negative emotional reaction to direct light) or the child may present with non-productive light gazing. As a result, the child may stare at the light table with decreased interest to the objects placed onto the light table (Wright).

CVI Suggestions Related to the ACTIVITY

- **Incorporate Function**
- **Repetition, Constancy and Routine**
- **Moving Objects**
- **Social Play**
- **Build Conversations that are Important to the Child**
- **Visual Communications Systems**
- **Cultural Considerations**
- **Touch**
- **Toys and Objects**
- **Technology**

Incorporate Function

Roman-Lantzy (2007) focuses on strategic adaptations of activities and the learning environment. She stresses that these adaptations are not a specific therapy but should overlay the child's daily educational routines. Roman-Lantzy and Ferell and Muir (1996) recommend incorporating specially designed activities and accommodations of the child's environment, but not utilizing discrete visual stimulation exercises, such as gazing at a flashlight.

The goal for the child is to experience optimal visual experiences to maximize visual attention and visual-motor activities throughout the day (Roman-Lantzy, 2007). For example, if a child successfully engages in visual gaze of a specific object, such as a red Mylar balloon, incorporate the red Mylar into various activities such as attaching red Mylar onto a cup or a communication board. Hyvärinen (2004) recommends activities to help the child integrate visual clues with other sensory input, such as working on vision in a warm bath or during eating and grooming.

Blanchette (n.d.) recently studied the visual behavior of three severely disabled students with CVI in her classroom. She took the multidisciplinary approach of integrating therapeutic services and specific environmental modification into functional daily routines in the classroom, rather than *pullout* of children for *vision stimulation*. Blanchette simplified the visual environment according to each student's visual needs as determined on the *CVI Range*, including color, high-contrast, and motion to facilitate visual recognition. After 12 weeks, all three children demonstrated gains in their ability to localize, fixate, and track a target, as measured on the *CVI Range*.

Repetition, Constancy, and Routine

Children benefit from constancy and routine. It may be helpful to keep constant the colors and background of a specific activity in order to correlate an activity, person and place in the room. It can be beneficial to *ritualize* routines, that is, the activity can have prescribed and familiar components and clear beginnings and endings in order to increase the child's sense of readiness and expectations, familiarity and enjoyment of the activity. For example, a specific storybook might be read in a particular location, with the same color background behind the reader, with consistent sound props, and identical hand motions and rhythms. A ritualized script could include specific visual input, language, and motions. Tactile, olfactory, or taste could be incorporated into the story, each time in the same manner and sequence. Specific cues can signal the beginning of the activity and the end of the activity. In developing a routine and rituals, remember that simplicity is the key. Progress very slowly to give the child time to process the information and learn.

Benefiting from repetition, children with CVI are more apt to look at familiar objects. Repetition and familiar routines help the child to build meaning and understanding, expectation of events, and a sense of control over their environment. Choose objects to view that are part of the child's everyday life such as a bowl, a spoon, and a hairbrush. Consider color, background, lighting, and movement when figuring out how to modify common objects.

Moving Objects

Many children will look more effectively if the object is moving, usually by lightly shaking the object. Mylar is often very effective for children with CVI, because it reflects and presents as a moving object. In a study by Cohen-Maitre and Haenrich (2005), they found that children with CVI responded better to movement of objects or self-movement as compared with the colors of object. The children however, responded best with simultaneous movement preferences and color preferences. The authors suggest that objects in specific school contexts maintain a specific color so that the child begins to associate color to function, for example, plates can always be red, and cups can be all blue across all settings.

Social and Play

Children with CVI are children and they want and need to play. Unfortunately, many children with CVI, especially children with concurrent motor disabilities do not have many opportunities to play. Often the children are passively moved about by staff to *make them* reach or touch something. Teachers sometimes limit social interactions to funny antics to make the child respond and laugh, although the child may not be actively engaged in the social interaction. It is essential to include the child as an active participant in the play partnership.

Expand play to actively involve the child. For example, if the child laughs when the teacher says, "Moo" while pretending to be a cow, figure out creative ways to include the child in the game. The child can help to touch an output switch that is programmed to tell the teacher to "Moo quiet" or "Moo loud". Alternatively, the child can help put a cardboard roll with bright colored textured fabric towards the teacher's mouth to direct the teacher saying "Moo" into the tube.

It is often beneficial to *bookend* a familiar activity by creating a routine or ritual to inform the child when the activity begins and ends (Groenveld & Jan, 1990). The beginning and ending can be ritualized by a special clap sequence, song, object symbol, or entry and exit from a specific location in the classroom. Children gain a sense of expectation from being told "last time" of an activity, by saying or signing 'last time', giving the child a *last time* object symbol, or using a five bead abacus. Many children learn math concepts through set repetitions of activities. The team can create a five-bead *abacus* by placing five large, variously textured beads onto heavy elastic cord that attaches to a rectangular piece of cardboard or Masonite. After each task repetition, help the child to slide a bead along the elastic cord to count and record the completed repetitions.

Build Conversations that are Important to the Child

Consider the child's interests and experiences to build conversations with the child. What does the child like to do or say? What interests the child or makes him/her laugh, brighten his/her expressions, or improve his/her behavioral state? The child's portion of the conversation may include initiation or imitation of vocalizations, signs and gestures, eye gaze, attentiveness, facial expressions, movements, activation of switches or changes in muscle tone.

Try to expand a learning activity into a two-part sequence where the child participates in one of the two parts. Two part activities build the child's sense of rhythm and timing, anticipation, turn taking and social interaction. Offer confirmation of the child's role. For example, consider the previous play sequence of the 'Moo' game. After the child helps bring the roll to the teacher's mouth, the teacher can confirm, "Yes, red roll. I said, "Moo". After building familiarity and routine with an activity, experiment with expanding the activity. Use a different color or different texture tube and say, "Neigh". After building familiarity with the new tube, offer the child a choice between the two tubes in order to direct the teacher to say "Moo" or "Neigh".

If the teacher/therapist is not sure of the meaning or the function of the child's verbal or non-verbal responses, s/he should communicate his /her best guess to the child. With low functioning children, keep language very simple and short. For example, if the child smiles after the teacher loudly said "Moo", the teacher might confirm and then ask, "Yes, loud Moo. Want more loud Moo?" Alternatively, the child can choose between two voice-activated switches with appropriate visual adaptations, "Moo loud," and "Moo soft". By making a choice, the child gains power by *directing* the teacher/therapist. Many children love the powerful act of directing teachers to do what they want.

Often children with severe disabilities prefer direct manual play with their body, such as helping them drum their hands on a brightly colored mat, rather than incorporating toys. During physical play, vision can be encouraged by the teacher/therapist wearing bright gloves. To build routine, visual interest, and sense of expectation, wear different color and textured gloves during specific tactile activities. The child can choose different color or texture gloves for specific conversations of games. The teacher or therapist can also build language and play activities by varying the physical components of touch, such as force (hard or soft), speed (fast or slow), rhythms, and location of touch.

Visual Communication Systems

When designing a child's visual communication system, consider factors such as complexity, crowdedness, colors, size, and background of the pictures or photos. Can the child adequately perceive and understand what the picture represents? Does the child better understand two-dimensional or three-dimensional symbols? Is the light box the most effective background for the communication system? Does the child recognize faces, expressions, and objects? The speech and language pathologist is a vital member of the team to help collaboratively design an effective communication system.

Cultural considerations

To boost the child's sense of familiarity and interest, it is beneficial to include music, sounds, foods, and symbols that are meaningful within the child's cultural experiences. Learn a few important words in the child's native language and sometimes talk in the child's language. Many immigrant students with severe disabilities may not understand English although they have been in school for many years. This may be attributed to poor attendance secondary to illness, decreased cognition, language processing, or not having sufficient meaningful experiences to align spoken word with visual and movement experiences. By learning a few words related to specific activities and motor requests in the child's native language, many children demonstrate significantly increased engagement and visual-motor skills.

Touch

Most children with CVI like touch and learn from touch. Each child usually has types of touch that he/she strongly likes and strongly dislikes. All children learn through their bodies. Some children with CVI in fact, may prefer play and interactions via direct touch rather than playing with toys.

There are many kinds of therapeutic and communicative touch and the IEP team needs to carefully note where, when, and how to incorporate touch so the child responds positively. Considerations include deepness of pressure, speed, and patterns of movement, and location of touch.

Touch can help define routines, such as clapping a child's feet together during a specific song. Many children love vibrators and enjoy vibrators with temperature options. Visual skills can be incorporated into tactile experiences, such as creating a routine of looking before assisted touching. For a child with limited movement, develop a short and simple routine that incorporates a sense of rythmicity. An example of a physical touch play routine might be- Shine a flashlight on the child's right hand. Wait quietly for the child to look. Then squeeze the child's right hand while counting aloud to five. Squeeze harder at the count of number five or have the child move the bead on the counting abacus (described in the Social and Play section) to signal the transition to the next hand. Repeat this vision-touch sequence, back and forth with each hand.

Children often enjoy sensory materials such as bins of rice, water, shaving cream, and various textured surfaces. For example, using a bin of shredded Mylar, say "Look, shiny paper", wait for the child to look, then help the child slowly reach and move his/hand hand back and forth in the bin. Use language ('Hand up, Hand down") to describe the motor movements of the activity to promote motor learning. Use simple language sequences to build expectation, rhythm, communication, and enjoyment.

Many children gain visual understanding and skills with their hands. Because seeing and cognition are more abstract than touching, touching an object may help the brain make sense of vision. Physical cuing and guiding may sometimes be more beneficial than verbal prompts for executing specific tasks, as processing auditory information may interfere with vision and motor exploration (Burkhart, 2003). Improve functional vision by helping the child touch the item that he/she is looking at. Verbally cue the child to the name, location, or characteristics of the object to facilitate visual exploration and understanding of the object.

Toys and objects

There are many components to consider when choosing toys or learning materials such as its weight, temperature, sound, size, smell, vibration, and texture. Certain toys may reinforce a child's preferred sensory modalities (Greeley, 1997). Give the child plenty of time to acclimate to a new object. If the child refuses the new object, consider that children with CVI often like familiarity, so gradually reintroduce the object to help build familiarity. Introduce a new object or learning activity in a familiar and quiet place, without distractions (Greeley).

Many toys are made from plastic and offer limited tactile variety and interest for a child with severe CVI. Everyday objects are often better for tactile and olfactory interest. Everyday objects build on familiarity and routine, such as rolling a watermelon back and forth, banging two shoes together, zipping the zipper up and down, or sorting spoons and forks. As some children may lock their vision onto light sources, some children may be stuck listening to electronic sounds, such as fans and electronic toys that make sounds. The teacher may need to turn off the electronic toy or activity (Greeley, 1997).

Technology

The variable brightness of the computer monitor can be very effective for children with CVI. Screen savers with simple bright pictures can be used to promote vision or for making choices (APH-CVI, 2009). The pictures can be programmed to jitter or shake using Intellitools or other software. Big switches can be adapted with Mylar or bright textured materials to gain a child's visual interest. The expanse of technology options for children with CVI is beyond the scope of this manual. Linda Burkhart offers excellent technology and communication suggestions for children with CVI on her website, http://www.lburkhart.com

CVI Suggestions Related to TEACHERS AND THERAPISTS

- **Limit Staff**
- **Slow Down**
- **Physical Assistance**
- **Have Fun**

At the core of learning, the teacher/therapist builds trust and facilitates social relationships. The quality of the teacher/therapist's relationship with the child is crucial to the child's social engagement and quality of life. Social isolation is possibly the most debilitating result of severe CVI. Through qualities of sensitivity, persistence, and compassion, the teacher/therapist is granted the opportunity to help the child expand his/her participation in the world and make meaningful social connections.

Limit staff

Some children with CVI love lots of social interchange and welcome many people into their lives. Changes are difficult for other children with CVI and these children may benefit from relating to a limited number of staff so they can become familiar with the specific styles, voices, and touch of a small number of teachers and therapists. Some children perceive and understand similar tasks differently when administered by different staff (Groenveld, 1990). In the situations where limited staff are involved with the child, additional IEP team members can serve important functions of team coaching, offering feedback and support, and helping to adapt activities and environments.

Slow down

Children with CVI often need more time to process input because their visual motor system is not functioning efficiently. The children may need a longer time to explore toys and objects (Groenveld, 1990). Give the child adequate time. Slow your movements and your words and wait a long time for responses. Initially wait quietly for a full minute of response time before assisting the child initially (Greeley). Talk slow, touch slow, move slow, and WAIT! Create rythmicity and expectation by developing routines of talking, waiting, helping when needed, waiting again.

Physical assistance

Resist the tendency to physically move a child's hands (Greeley, 2007). Some children with neurological disturbances are tactilely defensive. This means that they respond negatively, with a fright or flight response, to certain types of touch. There is a variety of ways to lessen the effects of tactile defensiveness. Explore the toy together with the child by having the teacher place her/his hands under the child's hands. By placing the child's hands on top of the teacher/therapist's hands, the child receives clear kinesthetic feedback of the desired movements that increases a child's perceptions of safety and familiarity (Greeley). Talk with your occupational therapist for suggestions to decrease sensory defensiveness and incorporate sensory activities into the child's daily program.

Have fun

It is important to incorporate activities that are silly, joyous, and playful, and amuse both the adult and the child. All children like to play and to have fun. Children with disabilities need to play more and have more fun! Children with CVI need teachers and therapists to play with them! A social/play session can be quiet, exuberant, expectant, turn taking and playful to create close connection between the teacher/therapist and child.

Carefully consider the type, intensity, and length of sensory information and social interchange (Morse, 1999). Be gentle and approach the child slowly and respectfully. Provide forewarning to the child before initiating touch, making noises, presenting bright or stimulating stimuli or moving him/her. Gently invite the child to participate. Try to enter the child's world. Figure out creative ways to engage and play with the child, rather than trying to instruct him/her to do something.

SUMMARY

CVI is a complex disability that affects all aspects of a child's school and home participation. To promote active vision and learning, professionals need to collaboratively develop a school program that incorporates the child's strengths and interests, visual goals and his/her needs for meaningful academic, social, self-help, and play activities. In the broadest sense, the child with CVI truly needs the teacher, therapist, and parent to engage meaningfully with his/her world.

Visual function is a psychological and emotional process as well as a physiological process (Morse, 1999). The child must have a desire and motivation to use his/her vision (Morse). Children will best utilize their visual system when they feel motivated and safe and when visual stimuli are presented at the child's present visual level. Children with CVI require familiar and meaningful activities embedded in familiar routines.

Because of the brain's ability to form new visual pathways, children with CVI have the potential to expand their visual motor skills and interactions with the visual world. By helping children with CVI improve his/her vision and his/her active participation in school, the children has the possibility of increased school performance and quality of life. Today, together, we are entering a hopeful and promising time to teach children with CVI.

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CHAPTER V

SUMMARY

CVI is the leading cause of visual impairment of children in the western world (Hoyt, 2003; Ketpal & Donahue, 2007). Children with CVI, despite normal ocular structures, cannot adequately process and interpret visual images because of damage to the visual areas of the brain (Good, et al., 1994). Many children with CVI have additional visual and neurological disabilities and as a result, children with CVI tend to have complex medical and educational needs (Hatton, et al., 2007; Hoyt, R.Burden, Hoyt, C., & Good, 1999). With an influx of children diagnosed with CVI entering school districts, IEP teams must have a strong foundation of knowledge about CVI and learn effectively strategies to serve the complex educational needs of these children. Until the past few years, there has been little information available to guide IEP teams who work with children with CVI. Recently, encouraging literature has been published which presents specific educational strategies to ameliorate the child's visual capacities (Roman-Lantzy, 2007). However, to date, educational literature is not available which addresses the children's multifaceted educational needs necessary to promote their successful participation in the school context.

The purpose of this scholarly project is to design a CVI manual for IEP teams working with children with CVI. The manual, *A Team Approach to CVI in Schools,* will help fill the gap for a school guide to promote school participation for children with CVI.

Whereas recent literature focuses importantly on the visual needs of the children, this manual addresses the broader needs of the *whole* child to participate more fully in school.

This scholarly project involved an in-depth review of the current literature regarding the etiology and onset, classification, evaluation and intervention of children with CVI. The literature review corroborates the need for transdisciplinary school teams to collaboratively evaluate and provide effective educational interventions for these children. CVI literature supports the educational premise of incorporating teachers and specialists into the children's daily program they learn best through familiar activities embedded into ritualized routines (Good, et al., 2001; Hyvärinen, 2004). School professionals need to understand the visual world of children with CVI and how disturbed visual perceptions, no matter how mild, significantly affect the child's overall development and school participation (Hyvärinen, 2005; Dutton, 2005).

The *Occupational Therapy Practice Framework, Domain and Process, 2nd Edition (2008)* was utilized to develop the CVI manual. Although the manual is designed for use by all member of an IEP team working with a child with CVI, the manual is guided by the central construct of the OT Framework, that is, engagement in occupation promotes health and participation in life. Children with CVI present with significant and profound limitations in occupational performance in the areas of education, play, leisure, and social participation. The CMOP (Law, et al., 1997) also helped guide the development of the CVI manual. The CMOP promotes client-centered practice and honors spirituality as the core of the client. The CVI manual similarly values the child's spirituality by focusing on his/her need for play and fun, social connection, choice making and meaningful occupations. The Person-Environment-Occupation Model (PEO;

Dunbar, 2007), developed by Law and Dunbar, also provided theoretical underpinnings to the CVI manual. The PEO focuses on the transactional relationships between person, occupation, and environment. The CVI manual organizes its interventions and strategies into the three factors of person, activity, and environment. The manual also focuses on the essential role of the teacher/therapist in both creating valuable social and play liaisons with the child as well as promoting the child's occupational performance.

The focus of the CVI scholarly project is the development of a written CVI manual for school professionals working with a child with CVI. This manual provides important but limited staff training to meet the learning needs of its diverse professional readers. The CVI manual strives to balance the need to explain and define complex medical and physiological CVI information with the need to moderate medical explanations and terminology to meet the needs of non-medical staff. The IEP members, with varied medical and educational training, would benefit from additional modes to learn about CVI. Notably, the addition of a CVI in-service is recommended to include audiovisual presentations of educational interventions with students with CVI. Additionally, throughout this project, the author has stressed the importance of a collaborative and transdisciplinary approach to training and teaching. Because one person wrote the CVI manual, it would be advantageous for a team of interested professionals to collaboratively present subsequent CVI learning activities and periodically update the CVI manual with current information and educational strategies.

By IEP teams working collaboratively with children with CVI, the teams can help improve the children's vision, school performance, and active participation in school. The

CVI manual, *A Team Approach to CVI in Schools* strives to promote occupational performance, well-being, and quality of life for children with CVI.

APPENDIX A

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G N Dutton

Volume number

17

Issue number

3

Pages

289-304

Year of publication

2003

Portion used

Figures / tables

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