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

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Note from the Author

I have been an occupational therapist for over 25 years and presently work as an OT in the Highline School District in Burien, Washington. *A Team Approach to CVI in Schools* was written as a partial requirement for a master's degree in occupational therapy, through the University of North Dakota. I would like to thank my UND project adviser, Cindy Janssen, MOT, for her delightful encouragement, wide-angle view of occupational therapy, and overall guidance. Warm thanks to my students with CVI and multiple disabilities, past and present, who have taught me about human connection and play. A huge thank you to Dr. Roman-Lantzy, who has led the way for children with CVI and led me on the path to learn about CVI.

I hope this CVI manual proves useful to school IEP teams working with children with CVI. IEP teams, parents, agencies, and individuals are welcome to add this manual to their resource lists and reproduce it for educational purposes.

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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 his/her 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 his/her 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. Recently, new educational strategies have 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, visual problems can also result from impaired eye movements, focusing problems, or damage to the visual processing areas of the brain. This manual focuses on visual problems resulting from disorders of the brain, which affect visual function (Dutton & Jacobson, 2002). 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 not a single set of universal CVI activities recommended for children with CVI. Rather, the IEP team needs to develop an effective, specific, and individualized plan. By addressing the child's strengths, weaknesses, and interests, the IEP team strives 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 through 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 changing needs. Additionally, each team member relies on the expertise of the team to evolve and expand his/her individual skills, in order 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, vision therapy, or speech therapy. Rather, to promote effective learning, teachers, and specialists should cross discipline boundaries and 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 and 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 s/he works the most with students and can offer ideas of successful strategies.

CVI Expert

- Professionals with experience or expertise working 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 deaf-blind children, birth through 21. Many of the projects offer information and expertise about visual disabilities and CVI.

To locate your state project for deaf-blind children-

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 with CVI, 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. The location of the damage along the visual pathways distinguishes lower and higher level cortical visual impairment.

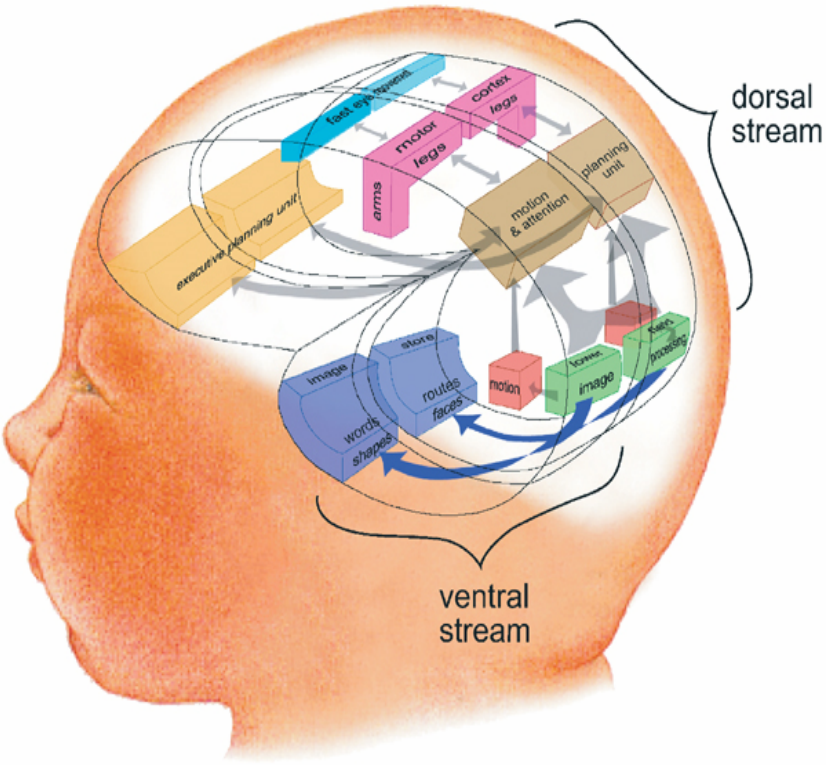
LOWER LEVEL CVI- Damage of the visual pathway up to and including the striate cortex is known as lower level CVI. Lower level CVI affects the child's acuity, understanding of the visual image, and ability to see various parts of the visual fields. Lower level CVI vision may vary in severity and type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

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



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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 much of the 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).

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 from 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 type, location, and age of onset of brain damage, which might have resulted in cortical visual dysfunction.

Causes of CVI include

- Meningitis and encephalitis
- Hypoxic- ischemic encephalopathy at term
- Brain malformation and syndromes
- Metabolic and neurodegenerative diseases
- Physical abuse
- Hydrocephalus
- Drugs and Poisons
- Near-drowning, seizures
- Neonatal herpes simples

(Good et al., 1994)

In each case listed above, oxygen deprivation in the brain results in damage to cerebral pathways and brain structures that 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 one ophthalmologic deficit. Additionally, many children with CVI have oculomotor deficits such as difficulty 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 LEVELS 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 and symptoms (Roman-Lantzy, 2007).

Roman-Lantzy 10 Characteristics/ Symptoms of CVI

1) Color preference
2) Need for movement
3) Visual latency
4) Visual field preferences
5) Decreased visual complexity
6) Light-gazing & non-purposeful gaze
7) Decreased distance viewing
8) Atypical visual reflexes
9) Decreased visual novelty
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 and 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 his/her 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 a specific 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 visual skills of both 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 faces 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 direction that 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 parents' visual history and simply playing children to see how well they use their vision is 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). Roman-Lantzy offers a structured method for professionals to evaluate functional vision of a child with suspected CVI (Roman-Lantzy, 2007)

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 a 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 each of the CVI characteristics, visual performance, relation between motor function and vision, and overall school participation in specific school environments.
- Direct evaluation of visual skills and deficits, led by the TVI (Teacher of the Visually Impaired).

The *Evaluation of Student with CVI* worksheet (see page 42) 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* (see page 45). 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:

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

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, children with CVI may have difficulties with basic self-regulation, rythmicity, and 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 merge elements that are reinforcing and interesting to the child, such as sound, familiar objects,

rhythm, song, and movement. Silliness and playfulness 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 7) 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 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 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 (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 a simple, desirable picture can encourage vision. After the child looks at the screen, a 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). Before expecting the child to look or reach, it is sometimes helpful 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 (Roman-Lantzy, 2007).

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**

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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 Roman-Lantzy's *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 (Roman-Lantzy, 2007). In a study by Cohen-Maitre and Haenrich (2005), children with CVI responded better visually to moving 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 *abacu*s 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 cardboard 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. Try 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 or 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 objects, 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, and 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 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, 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, introduce 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 consistent verbal language, such as "Hand up, hand down" to describe the motor movements of the activity and 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 cue and physical guidance may sometimes be more beneficial than verbal prompts to help the child execute specific tasks, because 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, real objects are often better for tactile and olfactory interest. Everyday objects build on familiarity and routines. Try rolling a watermelon back and forth, banging two shoes together, zipping the zipper up and down, or sorting spoons and forks. Just 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. These children may benefit from socially 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 cases where limited staff is 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, 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, and 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, 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 the child. 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 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 their vision and active participation in school, the children have 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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