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**Phoenix
Children's**

Understanding the Impact of Dual Sensory Loss in Children with cCMV, in partnership with Midwestern University and Phoenix Children's Hospital

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Mimi Pruniski, OTR/L



Mimi Pruniski, OTR/L

- Mimi Pruniski has been an occupational therapist for 40+ years with experience working with young children with visual impairments in preschool, elementary school and early intervention settings. She has served as a program director as well as direct service provider serving families with children with a wide variety of special needs and abilities. She specializes in working with infants and young children with complex medical needs, feeding issues and sensory concerns.



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Disclosures

- **Presenter Disclosure:** Financial: Mimi Pruniski received an honorarium for this course. Non-financial: Mimi Pruniski has no relevant non-financial relationships to disclose. Financial: Patrice Jung received an honorarium for this course. Non-financial: Patrice Jung has no relevant non-financial relationships to disclose.
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Learning Outcomes

After this course, participants will be able to:

- Define dual sensory loss.
- Identify the major characteristics of cortical visual impairment.
- List 3 major identifiable values of early intervention for children with dual sensory loss.

Dual Sensory Loss – What does it Mean

- A person who has a degree of loss in both sight and hearing, the combination of which results in significant difficulties in accessing information
- About 80% have some degree of usable vision and/or hearing
- Other terminology
 - Deaf-blind
 - Combined vision and hearing loss
 - Dual sensory loss/Dual Sensory Impairment
 - Co-existing/Co-occurring vision and hearing loss
 - Sordociegos (Spanish for Deafblind)



Vision issues



- CVI (Cortical Visual Impairment)
 - Cortical blindness
 - Cerebral visual impairment
 - Cortical visual impairment
 - Neurological Vision Impairment
- Eye Muscle Issues

Vision Screening

- Vision Screening
 1. Birth through 1st month- Baby begins to focus on lights, faces, and object 8-15 inches away from face.
 2. Baby begins to follow slowly moving light, faces, and objects at near.
 3. Have an atypical blink reflex when tapped at bridge of the nose.
 4. Have an atypical visual threat response in children older than 6 months.
- Parent Interview



“When attempting to determine the cause of a child’s visual disability, CVI should be considered when the child has

1. A normal or near normal eye exam that cannot explain the child’s impaired vision
2. A history or presence of neurological problems
3. The presence of behavioral responses to visual stimuli that are unique to CVI”

* Cortical Visual Impairment: An Approach to Assessment and Intervention, by Christine Roman-Lantzy, copyright 2007, AFB Press, New York

Characteristics of CVI - Overview

- Color
- Movement
- Latency
- Visual Fields
- Complexity
- Light gazing/non-purposeful gaze
- Distance Viewing
- Visual Reflexive Response
- Visual Novelty
- Visual Motor

Explanation of CVI Characteristics

- Color preference - some children have a strong preference for a particular color. Often it is red or yellow
- Need for Movement - to initiate or sustain visual attention, often the object viewed or the child, needs to be moving
- Latency - Often it takes the child a few seconds or minutes to respond to an object being presented
- Field Preferences - Lower field loss is common. The child may have certain areas in his/her visual field that work best when presenting an object.
- Complexity - When an object being presented is complex or the environment surrounding the object is complex.



Explanation of CVI Characteristics (2)

- Need for light - The child may need light to be paired with the object to view the target. Additionally, there may be a lot of light gazing and non purposeful gazing.
- Difficulty with distance viewing - The child has difficulty looking at a target that is beyond a certain distance.
- Atypical visual reflexes - the blink reflex is absent or delayed
- Visual Novelty - Familiar toys, objects and targets are easier for the child to visually explore. There may be a lack of visual curiosity for new objects.
- Absence of Visually Guided Reach - The ability to look at and touch an object at the same time may be difficult.

What you may see...

- A classic characteristic of CVI is that a child might glance at something like a toy, look away, then reach for the object.
- Need more processing time; wait time (delayed response when looking)
- Preference for toys of a specific color, that light up or move
- Stare at light or sun coming through windows; staring at ceiling fans
- Feeling that the child is looking through you rather than at you
- The environment and physiological factors may affect the child's visual responses.



Info related to CVI



- Not always easy to diagnose
- Parents are often the best observers/reporters
- Don't wait for a diagnosis to implement intervention
- Early diagnosis and intervention is critical because of neuroplasticity
- Visual efficacy varies according to environment, health, sleep
- Due to various reasons, many children with CVI go undiagnosed or receive a late diagnosis.
- Specialists in the eyecare field, Pediatricians, and various providers are unaware of CVI and the appropriate methods that can be used to diagnose it.

Audiological considerations

- There are a range of possibilities for hearing loss with many having a sensorineural hearing loss
- Can be unilateral or bilateral
- It is possible for a child with cCMV to pass the newborn screening and then later develop hearing loss
- Very important to have regular hearing testing with an audiologist
- Variety of devices can be used
 - Behind the ear
 - BAHA (Bone-Anchored hearing aid)
 - Cochlear implants

What is the value of Early Intervention

- Help families to navigate a complicated social and medical system
- Help families understand the diagnosis/diagnoses and the implications in their everyday life. People are not always ready to hear information at the same time and having professionals in the child's home on a regular basis allows the family to continually ask questions and be hearing information repeatedly to provide opportunities for increased understanding.
- Help provide strategies and help move the child forward in the everyday routines of the family – based on a coaching model with the belief that the parent is the first and best teacher for the the child
- The sooner the child is referred, the better the outcome is for gaining functional life skills that will help them become better humans first and then more productive students and eventually members of society...



Key Guidelines when working with Dual Sensory Loss

- When introducing a new learning opportunity...
 - Just one thing
 - Clear the Clutter
 - Big, Bright, Bold
 - Give Me Time



Strategies and Interventions

- Positioning is important
- Simple and Clear
- Color Contrast
- Solid Backgrounds – grade complexity
- Eliminate Glare
- Experiment with light
- Wait time – sometimes beyond reasonable
- Consistent colors; note preferences



Strategies and Interventions (2)

- Movement is important
- Repeat, repeat, repeat
- Make changes slowly
- Watch for signs of fatigue, overstimulation
- Allow for break times



Materials-the Good and Bad



Play Strategies

- Use black invisboards, black sheets, or solid dark curtains to block out the clutter.



Play Strategies

- Use a tray from APH , cookie sheet, or shallow bin to provide boundaries



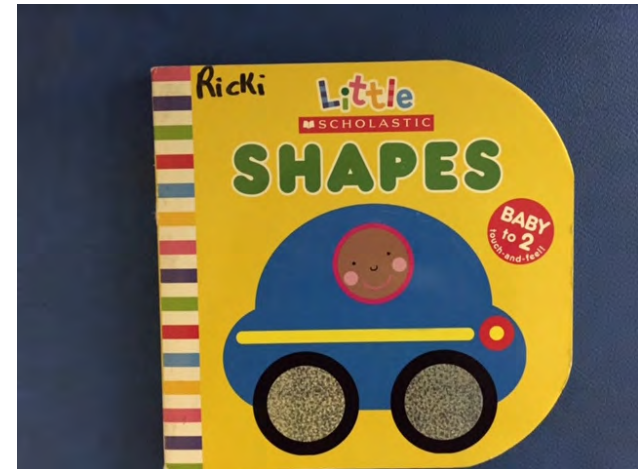
Play Strategies

- Use simple, high contrast toys/materials

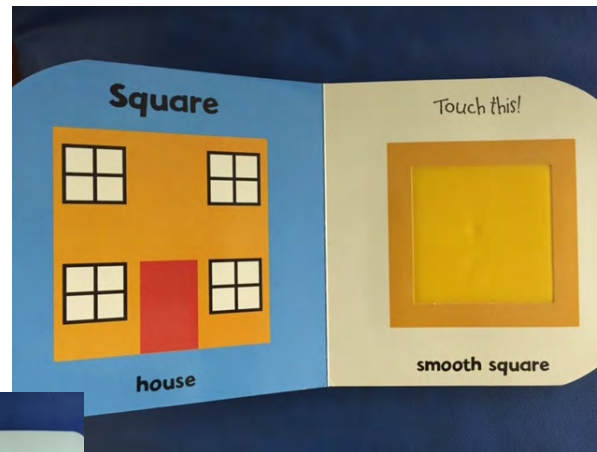
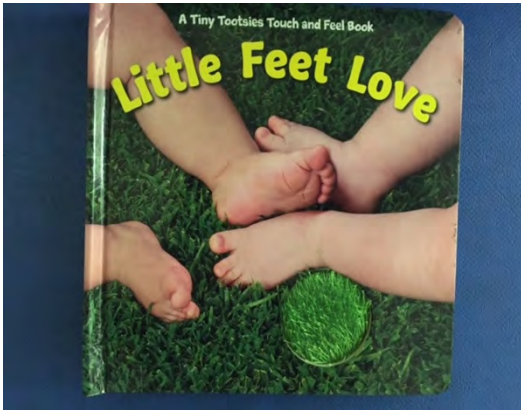


Early Literacy Strategies

- Print materials-
 - Books should try to have single clear pictures with minimal detail.
 - Good contrast

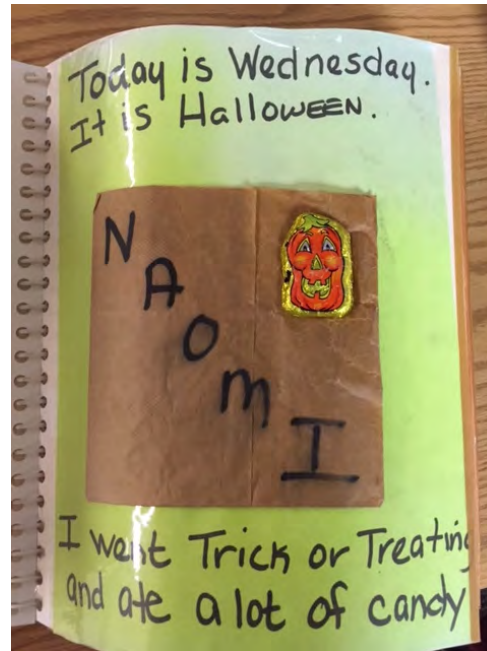


Early Literacy Strategies



- Print materials
 - Tactual Materials
 - Texture Book
 - Books such as Never Touch a Monster or Never Touch a Dinosaur by Rosie Greening (Author), Stuart Lynch (Illustrator)

Early Literacy Strategies



- Print materials-
 - Object Books.
 - Should be 3D
 - Be of high interest/meaningful to child
 - Multisensory – tactile, auditory

If in question... REFER

- Call your local pediatric ophthalmologist and/or pediatrician or audiologist
- Contact early intervention services
 - <https://azeip.azdes.gov/AzEIP/AzeipRef>
- Contact AZ Deaf Blind Project
 - <https://Azdeafblindproject.org>
- Contact National Center on Deafblindness
 - <https://www.nationaldb.org>
- A child with a unilateral hearing loss and vision loss is still eligible to receive services from the Deafblind Project in your state.

Services available through Statewide Deafblind Project

- Virtual or in-home consultation
- Training for your child's medical, educational, and therapy providers
- Connections to other families through hosted events, workshops, and drop-ins
- Assistance in attending workshops and conferences
- Guidance through transitional periods
 - Early childhood to preschool
 - One classroom to another
 - One school to another
 - School to adulthood



Strategies – iPad Apps for Vision

- Art Of Glow By Natenai Ariyatrakool
- Peekaboo Barn By Night & Day Studios
- Infant Zoo Lite By treebetty
- My Talking Picture Board by Little Bear Sees
- iLoveFireworks Lite By Fireworks Games
- fluidity HD By nebulus design
- Tap-N-See-Now by Little Bear Sees
- Cause and Effect Sensory Light Box By Cognable
- Big Bang Pictures By Inclusive Technology
- Bebot - Robot Synth By Normalware (review)
- Bloom HD By Opal Limited (review)
- EDA Play By EDA Play (review)
- Bubbles By Hog Bay Software (review)

References and Resources

- Roman-Lantzy, C. (2018). Cortical visual impairment: An approach to assessment and intervention, Second Edition. New York: AFB Press.
- Cortical Visual Impairment: Advanced Principles, copyright 2019 by Christine Roman-Lantzy. APH Press, Kentucky (www.aph.org)
- <http://littlebearssees.org/cvi-resources> Lists books, courses, organizations and support groups for CVI
- <http://www.perkinselearning.org/cvi-endorsement/resources> Has information for individuals wanting to get a CVI endorsement but also has some good resources with blogs, books, videos, etc.
- <http://tech.aph.org/cvi> APH materials for purchase or that can be received through federal quota (check with your state to see how this is accessed)
- 18 Vision Development Milestones From Birth to Baby's First Birthday, by P. Kay Nottingham Chaplin, EdD and Kira Balcionado, BA, copyright 2018 Prevent Blindness
- Childhood Vision Screening, by Mae Millicent W. Peterseim, MD, copyright 2018 American Academy of Ophthalmology

Early Referral is Essential



- A treatment method or an educational method that will work for one child may not work for another child. The one common denominator for all of the young children is that early intervention does work...Temple Grandin

Thank You!

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