Cortical Visual Impairment:

Session 1: Overview of Characteristics & Phases

FL & VI DB Collaborative
3-Part CVI Workshop
2025

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Overview of Series

- Outline & Resources
- Overall goals and agenda
  - Session 2: Unique Considerations for Functional Vision Assessment & Learning Media Assessment
  - Session 3: Approaches to Intervention and Educational Program Development

What is Cortical Visual Impairment?

- Vision loss due to damage or malformation in the brain that interferes with the child's ability to understand visual information coming from the eyes

- CVI is the leading cause of visual impairment in young children living in countries/regions with access to quality neonatal health care

  → *"a national health care crisis"?*

OSEP Policy Letter (2017)

It has come to our attention that some States direct their LEAs to implement a two-step process when addressing whether a child suspected of having a visual impairment may be eligible for special education and related services under the IDEA. During the first step, the eligibility team is required to reach a decision as to whether the child has one or more of the conditions that the State has identified and believes could affect a child's vision functioning. Examples of such conditions might include: the child has a reduced visual field to 50 degrees or less in the better eye; the child has been diagnosed with cortical visual impairment; or the child has a diagnosis of a degenerative condition that is likely to result in a significant loss of vision in the future. During the second step, the eligibility team determines the extent that it should proceed further and examine whether the condition adversely affects the child's educational performance.

→ State definitions generally updated since 2017

https://sites.ed.gov/idea/files/letter-on-visual-impairment-5-22-17.pdf

Legislation – Example (2021)

- Louisiana Senate Bill #126: "Establishes the Commission for Identifying Risk Factors for Cortical Visual Impairment"

AN ACT

To enact R.S. 36:259(B)(37) and R.S. 46:2271, relative to the establishment of the Commission for Identifying Risk Factors for Cortical Visual Impairment; to provide for legislative intent; to provide for definitions; to provide for a program to be established within the office of public health, Louisiana Department of Health; to provide for the responsibilities of the office in administering the program; to provide for membership of the commission; to provide for responsibilities of the commission; and to provide for related matters.

	LA	SB126	Intro	Establishes the Commission for Identifying Risk Factors for Cortical Visual Impairment. (8/1/20) [Detail] [Text] [Discuss]	**2020-03-09** To Senate Health & Welfare Committee

→ *died in committee, March 2020*

https://legiscan.com/LA/pending/senate-health-welfare-committee/id/1182

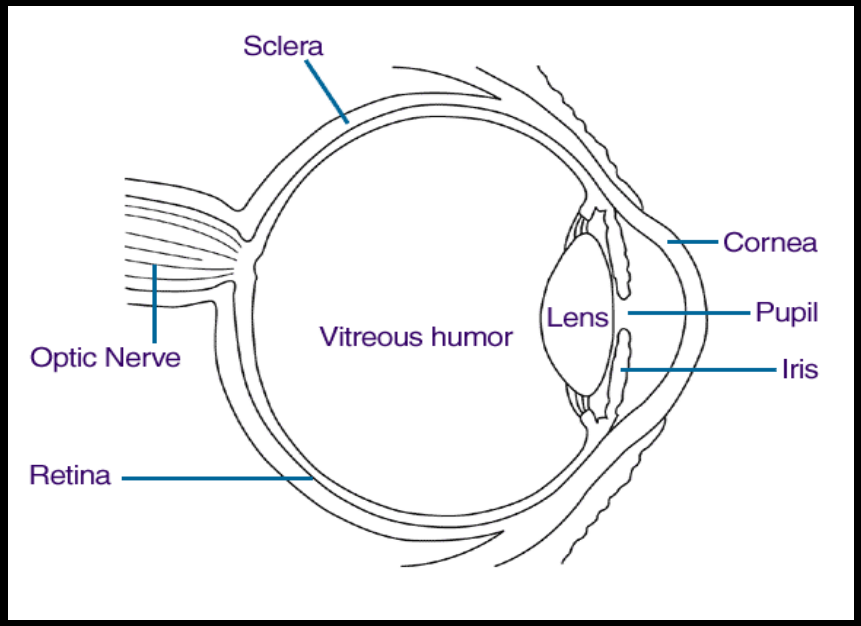
Infant Vision Screening for CVI

- Pilot phase – can be done informally in the meantime **NOT diagnostic*
- Up until 10 months

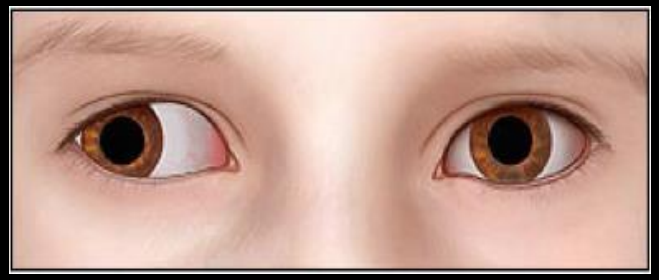
- Blink to touch
- Orients toward faces
- Defends to bright light

- *Refer for informal recommendations and possible follow-up clinical assessment*

CVI is different from other non-brain related visual impairments



- Acuity loss
- Field loss
- Contrast sensitivity
- Impact of ocular motor conditions
- Progressive/stable?



- Children with CVI *can* have additional ocular visual conditions

CVI is suspected when:

✓ History of brain injury or malformation

✓ Medical eye exam cannot explain level of visual impairment / abnormal use of vision

✓ Presence of unique visual characteristics

→ ***What is cerebral visual impairment?***

Medical history significant for CVI

- Asphyxia/Hypoxic-ischemic encephalopathy (HIE)
- Periventricular leukomalacia (PVL)
- Seizure disorders
- CVA/stroke
- Intraventricular hemorrhage (IVH)
- Infection
- Structural anomalies
- Trauma, TBI
- Metabolic disorders
- Cerebral Palsy (an *associated* condition)
- *Prematurity* (not a *cause*)

Are you familiar with your student(s) medical history / possible causes?

The clinical eye report results were "normal" or "unable to test" – but I know that the child's visual functioning is not typical.

- Does the clinical vision specialist (ophth/opt) recognize or diagnose CVI?
- If NOT, go to a low vision specialist who does
  - Neuro-ophthalmologist

- Follow-up clinical assessment with Functional Vision Assessment

Why is it important to identify and assess?

- Specific interventions to IMPROVE visual functioning
  - Based on assessment
  - Different approaches depending on where the student falls on the RANGE of visual functioning
- Intervention is a TEAM EFFORT
  - Not just the TVI, not just the classroom, not just the family

Frequently Asked Questions:

Who can diagnose CVI?

An ophthalmologist, neuro-ophthalmologist, optometrist, neurologist, or other clinical specialist.

The eye exam said "normal" or "unable to test" but I know that my child/student has atypical visual behaviors.

Make sure that the clinical specialist has knowledge of and ability to diagnose CVI before making the appointment. Clinical vision specialists who have expertise in the structure of the eyes may not necessarily be familiar with or able to diagnose CVI.

The functional vision assessment (FVA) did not address the unique characteristics of CVI.

You are entitled to educational assessments that are relevant to your child's specific visual condition(s). You can ask for an assessment that addresses the unique visual implications of CVI, which is very different from other ocular forms of visual impairment. A functional vision assessment is conducted by a licensed teacher of students with visual impairments (TVI), and provides unique information about the child's current visual functioning. This information is based on a thorough review of the impact of the child's visual condition(s), observation, interview with family/relevant professionals, and direct assessment. A functional vision assessment for a student with CVI must address the unique impact of CVI (i.e., the impact of the unique characteristics of CVI on the child's use of vision throughout the day).

I have heard other terms for CVI that are confusing, such as "cerebral visual impairment" or "cortical blindness."

"Cerebral visual impairment" is not the same as cortical visual impairment (Jan, 2010). Cerebral visual impairment refers to a larger "umbrella" category of neurological visual conditions, including dyslexia and synesthesia. "Cortical blindness" is an incorrect term, because individuals with CVI are never totally blind, in the absence of an additional ocular visual impairment. They always have *some* vision. Regardless of the terms used, it is important that assessment and intervention/educational services address the student's current visual functioning.

ADDITIONAL RESOURCES:

- Pediatric Cortical Visual Impairment Society family advocacy group with extensive resources on CVI
- "Statement on Cortical Visual Impairment" (Roman, Baker-Nobles, Dutton, Evans Luiselli, Flener, Jan, Lantzy, Matsuba, Mayer, Newcomb, & Nielsen, 2008)
- Roman on CVI YouTube Channel for a variety of short videos for families and professionals on CVI topics
- General resources for ideas on CVI:
  - Little Bear Sees family-oriented website and resources
  - West Virginia Dept. of Education & Georgia Sensory Assistance Project training resources and videos
  - Texas School for the Blind/Visually Impaired CVI resources
  - Kaleidescope: The Cortical Visual Impairment Podcast unique perspectives from families and professionals
  - Paths to Literacy resources and intervention ideas on CVI
  - Salient Features Collaborative – a website collaboration by professionals to support children with CVI
- National family teleconference group for families of children/youth with CVI (hosted by Lighthouse Guild International). Register here or for more information, contact Judith Millman (judithmillman@aol.com)
- *Professional development opportunities*:
- Perkins E-Learning online classes on a variety of topics related to CVI

DB/CVI Population Overview (NCDB, 2022)

- Average per state 30% of DB kids are identified as having CVI
- An additional 18% are “unknown” as to whether they have CVI

(*improved from 55% in 2019)

State	Yes	No	Unknown or Missing	Total
Puerto Rico	12	21	4	37
Rhode Island	25	19	4	48
South Carolina	46	80	32	158
South Dakota	12	25	5	42
Tennessee	132	142	19	293
Texas	251	567	22	840
Utah	58	79	0	137
Vermont	21	7	8	36
Virgin Islands	1	0	18	19
Virginia	55	82	28	165

- Extremely wide variance per state (4% - 58%)

https://ncdb-childcount-2022.netlify.app/03-02-cortical-visual-impairment-table

CVI Population Overview (ATLAS & NCDB, 2021)

- Higher percentage of augmentative and alternative communication [AAC] users
- A lower percentage of identified hearing loss but a higher percentage of “unknown” hearing loss as compared with children without CVI
- A higher percentage known to have multiple disabilities
- Significantly higher percentage of students with complex health care needs

(Karvonen et al., 2021)

What's happening in the brain

- Dorsal stream – "the where"

Movement, form, light, low acuity/detail

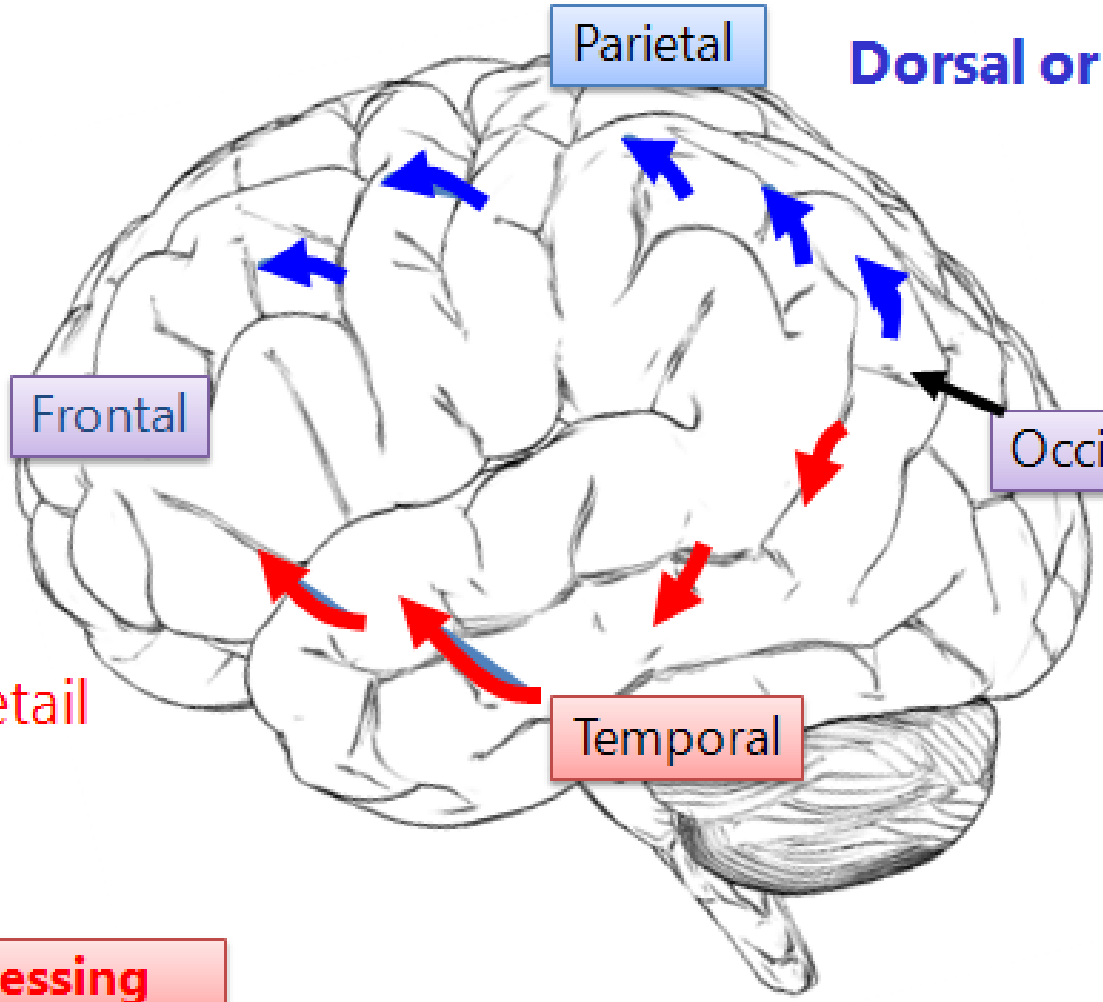
  - Move then find something, NOT find something then move

- Ventral stream – "the what"
  - Eye-to-object contact

Progress in visual functioning = integrating dorsal and ventral stream, then strengthening ventral stream

Roman, 2015; Roman, 2018

Dorsal and Ventral Streams



Dorsal or "where" stream

Spatial processing

location

movement

spatial transformations

spatial relations

color

texture

pictorial detail

shape

size

Object processing

Ventral or "what" stream

Dorsal/Ventral Simulation

Unique visual characteristics

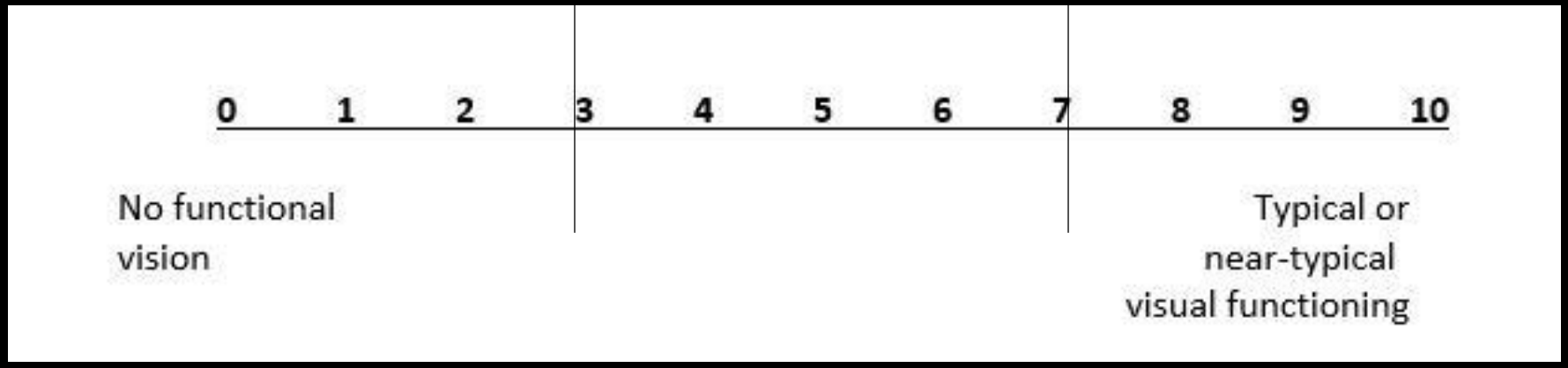
1. Color preference
2. Need for movement
3. Visual latency
4. Visual field preferences
5. Difficulties with complexity
6. Need for light
7. Difficulty with distance viewing
8. Atypical visual reflex responses
9. Difficulty with visual novelty
10. Absence of visually guided reach

Roman, 2007; Rev., 2018

Phases: Severity of CVI

- Severity of CVI is described in three phases
  - Severity = level of impact on visual functioning

Phase 1 (Severe) Phase 2 (Moderate) Phase 3 (Mild)



CVI phase determined by assessment using the CVI Range

Intervention must be guided by phase

CVI Characteristics

- How does each characteristic impact *visual functioning* ?
  - The child's ability to use his/her vision to access information throughout the day

- Characteristics affect vision differently as visual functioning *improves* along the RANGE

Color preference

1

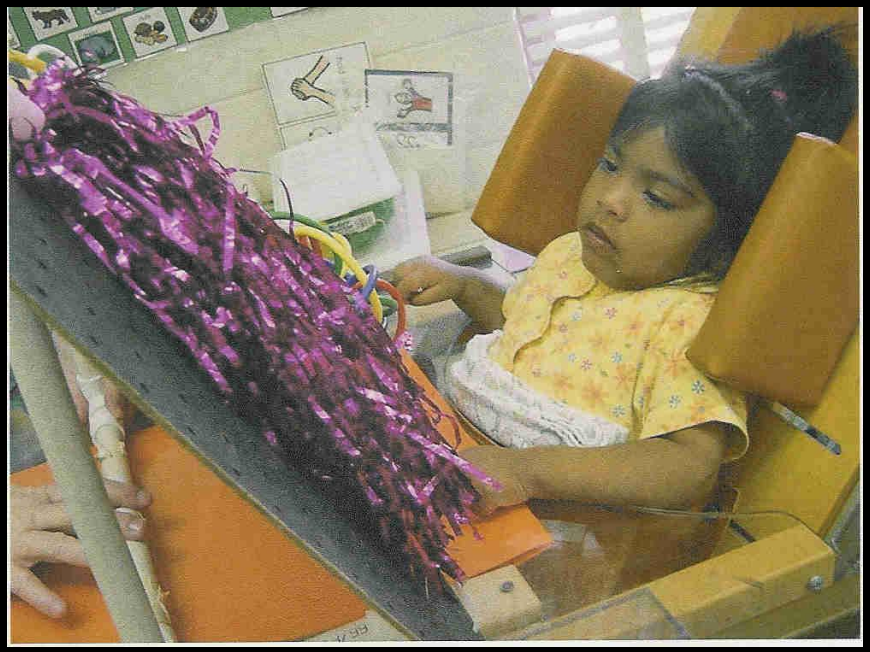
- Color vision is usually preserved in CVI
- Children often have a favorite color or will only look at certain colors (often red, yellow)

Further along the Range:

Benefit from color to highlight important information or provide an anchor

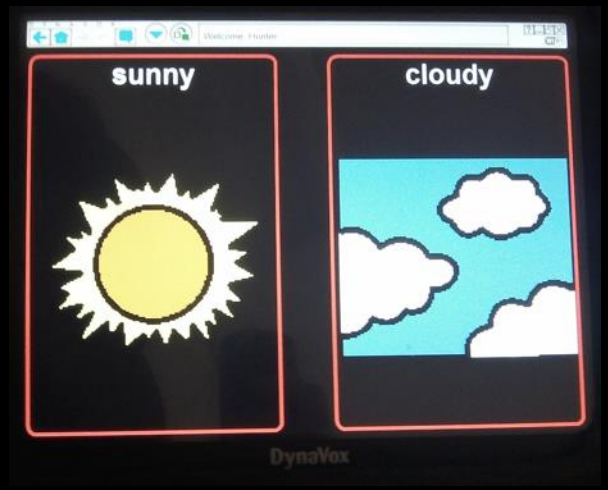
Using dorsal stream alone, you can get information on color.

"You don't even need a visual cortex to see red!"



Photograph from http://www.aph.org/cvi/


White Dog,
White Dog,
What do you see?
I see a black sheep
looking at me.


sunny
cloudy
DynaVox

Movement

- Need for movement to attract visual attention
- Need for movement to sustain visual attention

- Children with CVI may only look at something that moves or has movement quality (shiny)

- Often helps children with CVI with mobility

Further along the Range:

Movement at a distance
Movement for unfamiliar or complex materials

Visual latency

- The length of time between when a visual stimulus is presented and when the child looks at or orients towards the stimulus

- Different from motor latency and cognitive latency/processing delay

Further along the Range:

Latency decreases with "warm up"
Latency only when tired, stressed, overstimulated

Visual Field Preferences

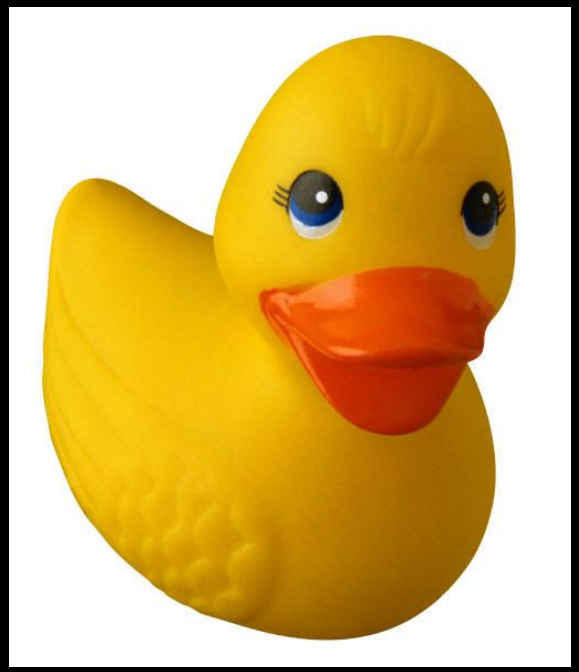
- Field *preferences*, not field *losses*
- Typical progression:
  - One strong peripheral field (R or L)
  - Then…both peripheral fields
  - Upper field
  - Central field
  - Lower field

Visual Complexity

5

Complexity of Array

Complexity of Target



Complexity of Faces

Complexity of faces overlaps with another characteristic: *Visual Novelty / Familiarity*

Complexity of the Sensory Environment

External:

- Lighting
- Noise, background
- Temperature
- Interaction/social
- Positioning, trunk support

Internal:

- Tired, hungry
- Pain, medication
- Emotional

It's not the child's VISION that is fluctuating from day to day…

It is the complexity of the environment (external and internal sensory input).

Need for Light

(Formerly "Light Gazing / Non-purposeful gaze")

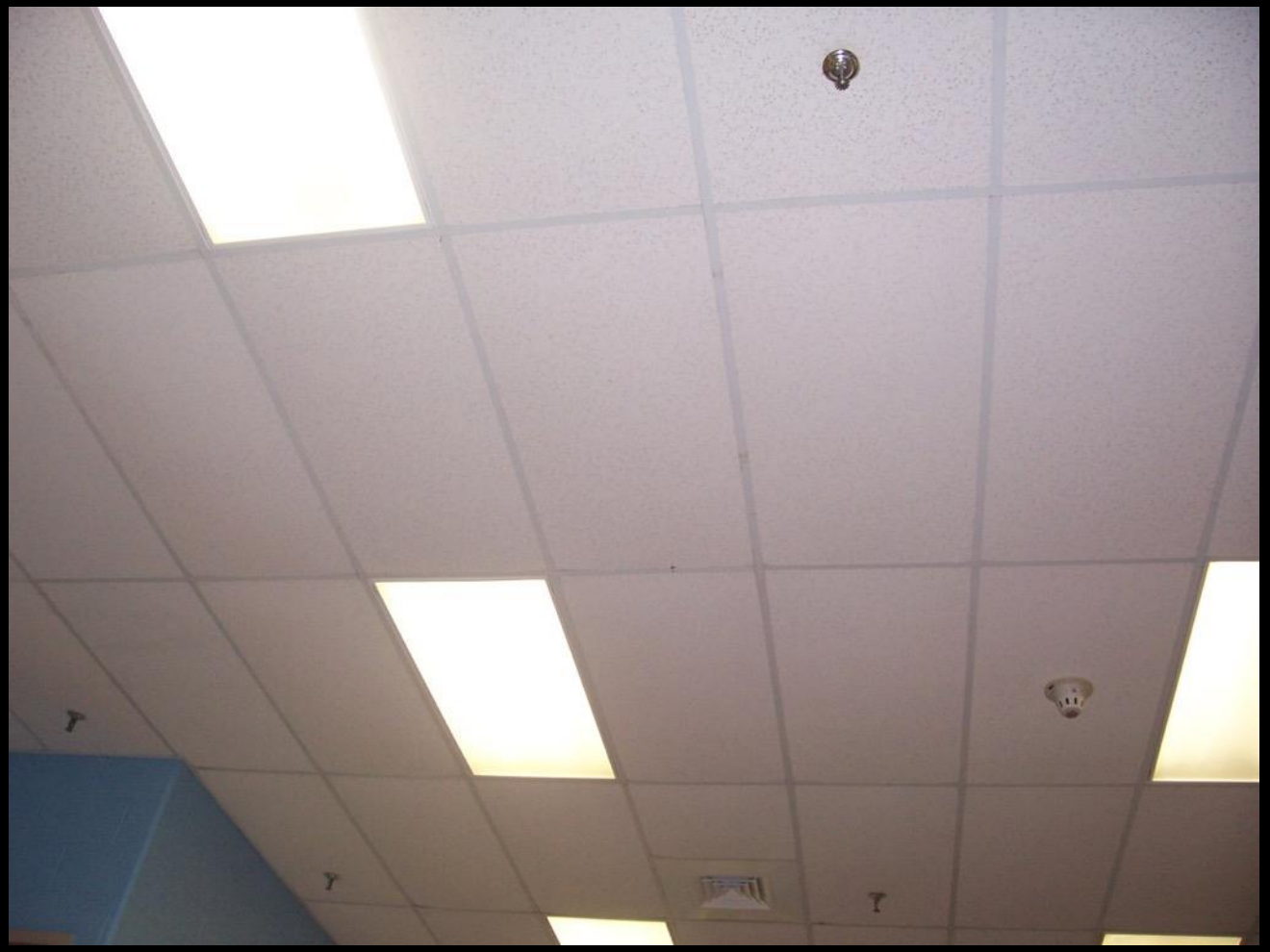
- "Light Gazing" – Attraction to bright, primary sources of light
- Non-purposeful gaze when not looking at an interesting target
  - OR when overstimulated, or trying to attend tactilely or auditorally

Non-purposeful gaze is purposeful!

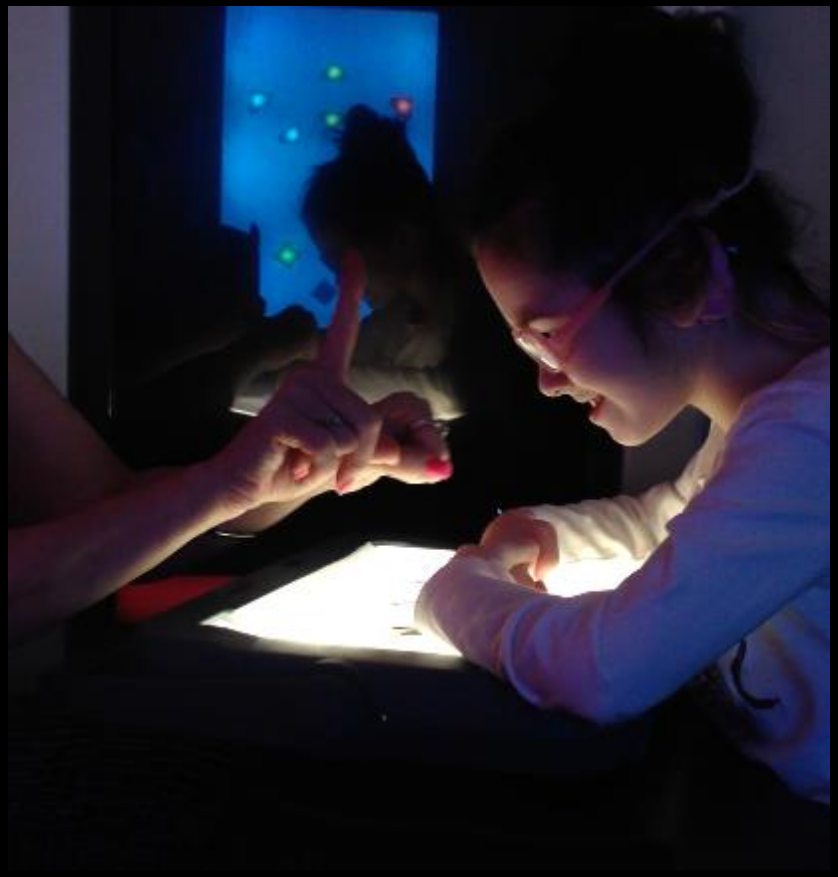
Light Gazing

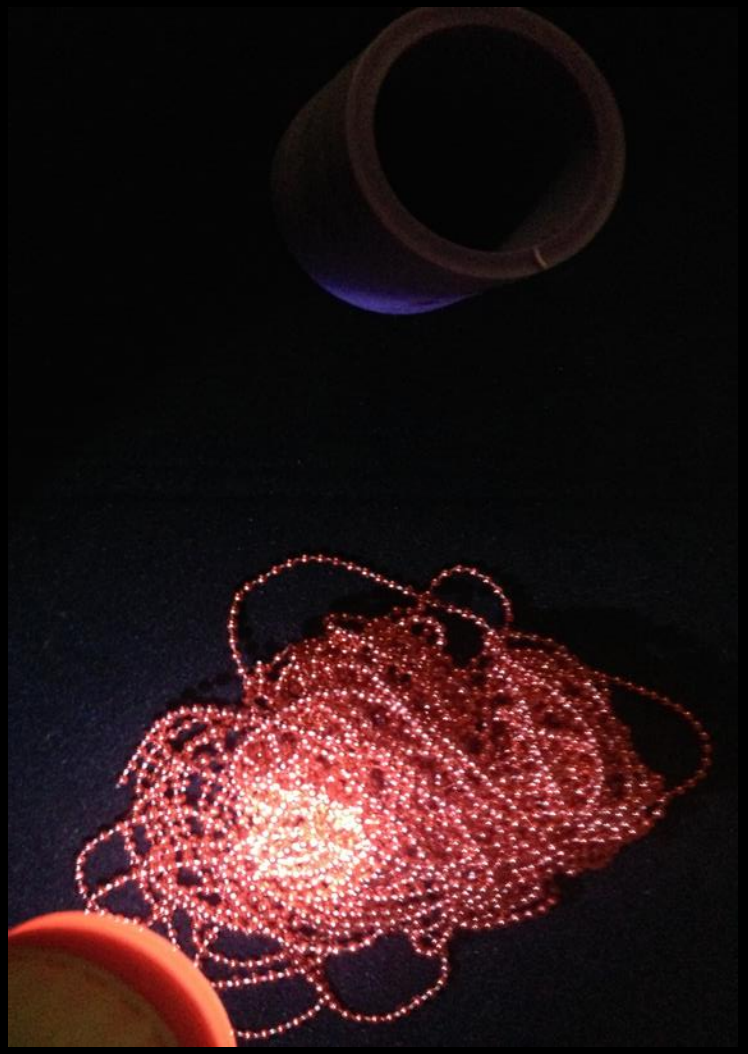
"Non-Purposeful Gaze"

Consider: View From a Tilted Chair



Light to Enhance Attending





Light to Enhance Attending

Difficulty with Distance Viewing 7

- Children with CVI can often only look at things close to them
- May be able to see targets a little further if moving, specific color, or brightly lit

Distance is related to *complexity*

Distance Viewing

Distance Viewing

Atypical Visual Reflexes

- Reflexes often absent, latent, or inconsistent
  - Blink to touch between eye brows
  - Blink to threat

Difficulty with Visual Novelty

- Children with CVI often look at familiar things better than novel (unfamiliar) items
- Novel environments can be challenging
- In typical visual processing, it's the opposite

Further along the Range:

Novel things that share characteristics of familiar
Novel things are difficult in complex environments

Name one thing in this photo

Familiarity is easier because CVI is about *learning*.

The child has learned to look at what is familiar.

Absence of Visually Guided Reach

- Children with CVI often have trouble using eyes and hands together
  - Often look, then look away, then reach
  - Some children cannot look at what they are holding
  - Some children need to touch something to look at it

VGR and motor impairments: think outside the box

"Look-look away-reach"

The Characteristics Overlap…

Color Light Movement Complexity

and so on…

COLOR PREFERENCE: - favorite/highly preferred colors - multiple colors on a visual target - need for bright/saturated colors to anchor visual attention	
NEED FOR MOVEMENT: - movement at near - movement at far - movement for complex or novel	
VISUAL LATENCY: - specific length of time - latency with novel or complex targets or environments - when tired, stressed, overstimulated	
VISUAL FIELD PREFERENCES: - left - right - center - upper - lower	
VISUAL COMPLEXITY: - array - target - sensory environment - faces	
NEED FOR LIGHT - attraction to light, light gazing, "non-purposeful gaze" - light to illuminate targets - backlighting e.g. on a screen/tablet	
DISTANCE VIEWING: - near: up to 18" - 2 to 3 feet - 4-6, 6-8, 10, 10-20'	
ATYPICAL VISUAL REFLEXIVES - blink to touch - blink to threat	
VISUAL NOVELTY: - only able to view familiar objects - novel objects that share [specific] characteristics with familiar - need for warm-up time - difficulty with novel environments	
VISUALLY GUIDED REACH: - Look-look away-reach - Look-reach-look away - Touch first, then look - Specific examples	

Phases: Severity of CVI

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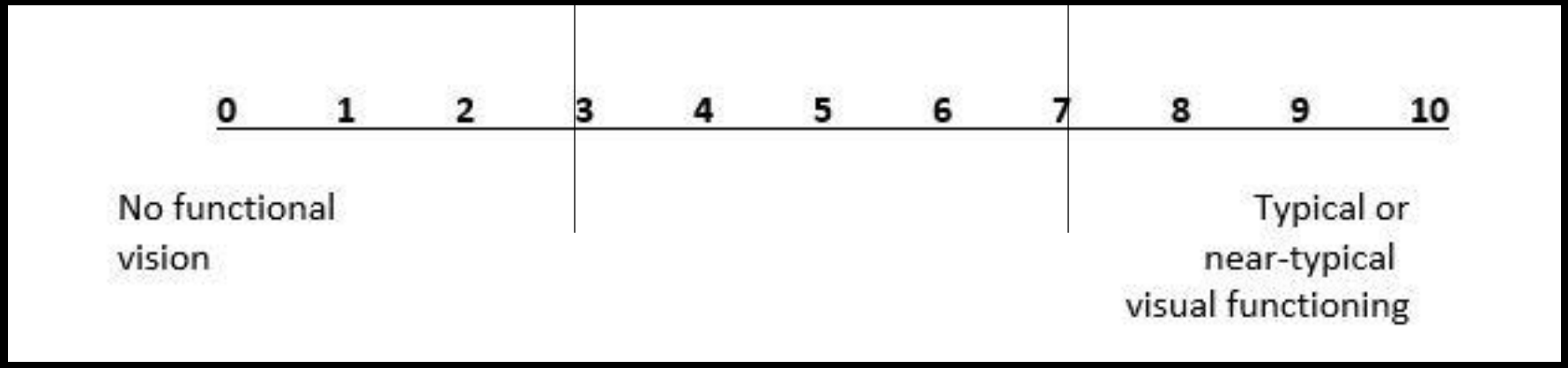
  - Severity = level of impact on visual functioning

Phase 1 Phase 2 Phase 3



CVI phase determined by assessment using the CVI Range

Intervention must be guided by phase

Phase I: 1 to 3

- Limited use of vision and cannot do anything else when they are "looking"
- Most CVI characteristics interfere with visual functioning

- The major goal of Phase I is building visual behavior
- We want to give the student practice "looking"

Phase II: 3 to 7

- Able to use vision in a variety of activities when given support and adaptations
- Much lower visual functioning without adaptations and support

Major goal is to begin to integrate vision with function

We want to give the child practice using vision in the context of daily routines and activities

"Early" vs "Late" Phase II

Eye-to-object contact:

- Starts at around 5 on the CVI Range
- Related to ventral stream processing
- Indicates initial readiness for higher order visual discrimination skills
  - Beginning of 2-D processing

How much should we expect the child to be using vision throughout the day?

Phase III: 7 to 10 (or almost 10)

- Children demonstrate visual curiosity
- Children can look at pictures and other 2-dimensional material
- Children can use their vision to learn about their environment

Major goal is refinement of the CVI characteristics

- Using vision for learning
- Unique visual characteristics of things ("salient")
- Generalizing visual information

Guess the Phase…

Steven:
https://www.youtube.com/watch?v=Owd1ReNmMJc

https://www.youtube.com/watch?v=ucpRJTaUHaY

https://www.youtube.com/watch?v=pKaPZOtHFcY

https://www.youtube.com/watch?v=HOT_OLcNZsA

Erin:
https://www.youtube.com/watch?v=j1pjg98k27I&feature=youtu.be

Phase I - Additional Resources

- Phase I (PCVIS): https://pcvis.vision/educators-and-therapists/phase-i-cvi/
- Roman on CVI – Object Selection in Phase I (Roman, 2019): https://www.youtube.com/watch?v=Pd210F37mu0
- Cause and Effect Light Box App: https://apps.apple.com/us/app/sensory-light-box/id533976433
- Cause and Effect Sound Box App: https://apps.apple.com/us/app/sensory-sound-box/id548622567

Phase II - Additional Resources

- Phase II (PCVIS.vision): https://pcvis.vision/educators-and-therapists/phase-ii-cvi/
- The What's the Complexity Framework (Tietjen, M.). In Roman-Lantzy, C. (2019) *Advanced Principles of Cortical Visual Impairment*. Louisville, KY: APH Press
- Tips for Providing Remote Video Instruction for Students with CVI (Allie Futtie/Perkins E-Learning, 2020): https://www.perkinselearning.org/technology/blog/tips-providing-remote-video-instruction-students-cvi
- CVI-Friendly Videos (Videos by Alissa Desousa, TVI; article by Diane Brauner/Perkins E-Learning, 2020) *: https://www.perkinselearning.org/technology/blog/cvi-friendly-videos-resources-students-cvi *Note age-appropriateness of videos, and child-specific CVI goals of your child/student with regard to 2-D processing and sight word identification
- Explain Everything app: https://explaineverything.com
- Animate/draw and record audio over images/photos

Phase III - Additional Resources

- Salient Features Collaborative: https://cvicollaborative.wixsite.com/salientfeatures

- The What's the Complexity Framework (Tietjen, M.). In Roman-Lantzy, C. (2019) *Advanced Principles of Cortical Visual Impairment*. Louisville, KY: APH Press

- Roman Word Bubbling App: http://roman-word-bubbling.appspot.com/

- Phase III (PCVIS): https://pcvis.vision/educators-and-therapists/phase-iii-cvi/

- Salient Features & Comparative Thought (PCVIS): https://pcvis.vision/educators-and-therapists/salient-features-and-comparative-thought/

- Roman on CVI - Digging Deeper: Comparative Thought (Roman, 2019): https://www.youtube.com/watch?time_continue=7&v=cKm9xUTeD1g&feature=emb_logo

General Resources

- Roman-Lantzy, C. (2018). Cortical visual impairment: An approach to assessment and intervention (2nd Ed.). Louisville, KY: APH Press

- Roman-Lantzy, C. (2019) *Advanced Principles of Cortical Visual Impairment*. Louisville, KY: APH Press

- CVI Resources: http://cviresources.com/services/blog/

- At Home: Everyday CVI Adaptations and Approaches (PCVIS): https://pcvis.vision/families-and-caregivers/at-home-everyday-cvi-adaptations-and-approaches/

- Roman on CVI (YouTube Channel): https://www.youtube.com/channel/UCx6owlBfWYCWd6SQc37wfwQ

- Kaleidoscope: The Cortical Visual Impairment Podcast: https://thecvipodcast.libsyn.com/

CDKL5 & CVI – Emergent Research Basis:

Brock, D., Fidell, A., Thomas, J., Juarez-Colunga, E., Benke, T. A., & Demarest, S. (2021). Cerebral visual impairment in CDKL5 deficiency disorder correlates with developmental achievement. *Journal of child neurology*, *36*(11), 974-980.

Demarest, S. T., Olson, H. E., Moss, A., Pestana-Knight, E., Zhang, X., Parikh, S., ... & Benke, T. A. (2019). CDKL5 deficiency disorder: Relationship between genotype, epilepsy, cortical visual impairment, and development. *Epilepsia*, *60*(8), 1733-1742.

Olson, H. E., Costantini, J. G., Swanson, L. C., Kaufmann, W. E., Benke, T. A., Fulton, A. B., ... & Heidary, G. (2021). Cerebral visual impairment in CDKL5 deficiency disorder: vision as an outcome measure. *Developmental Medicine & Child Neurology*, *63*(11), 1308-1315.

Quintiliani, M., Ricci, D., Petrianni, M., Leone, S., Orazi, L., Amore, F., ... & Battaglia, D. I. (2022). Cortical visual impairment in CDKL5 deficiency disorder. *Frontiers in Neurology*, *12*, 805745.

Thank you!

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