CVI, Communication Needs and AAC: A Structure to Success

John M. Costello
Director, Augmentative Communication Program
Children's Hospital Boston, MA
John.costello@childrens.harvard.edu
www.childrenshospital.org/acp

Agenda:

1. What is CVI?
2. Vision and the Brain.
3. Philosophy/goal
4. Typical IEP goals when not considering characteristics of CVI
5. focusing on language and language learning opportunities while trying to support vision.
6. characteristics of CVI supported by video examples when available and how these typically interfere with our standard intervention strategies.
7. questions

What is CVI?

- Used to describe a condition when a person is visually unresponsive but has a normal eye exam or an eye exam that can not explain the abnormal function
- The brain is unable to process the visual information sent to it from the eyes through the visual pathways

Etiology:

- At least 60% of children with neonatal hypoxic-ischemic encephalopathy have cerebral visual impairment.
- PVL (periventricular leukomalacia) in preterm infants (lower visual field, visual guidance, extracting information from a visually loaded environment)
- Head injury
- Infections
- Metabolic disease
- Multiple births

Cortical/Cerebral Visual Impairment

- "….is now the commonest cause of visual impairment in children in developing countries, is increasing in prevalence due to improved perinatal care and survival of young children with profound neurological disease"

Matusuba, et.al. 2006, Dev. Med. Child Neurology

Cerebral Visual Impairment

Functional Vision disorder

A neurological disorder resulting in bilateral impairment of visual acuity caused by damage to the CNS, meaning visual acuity is reduced as a result of non-ocular disease.

The impairment is due to damage to the visual cortex and/or the posterior visual pathways
(Jan&Groenveld,1993)

CVI

- Cortical Visual Impairment – bilateral damage to the visual pathways and/or the Occipital lobe. (Jan et al, 2000)
- Cerebral Visual Impairment/ Brain Damage related vision loss - damage to the cortex and also in other parts of the brain (Hyvarinen, 2004)

Visual disorder due to neurological damage

Vision and the brain

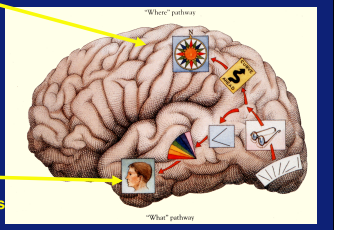
Much of vision is due to the processing of visual information

Estimated that over 40% of brain is devoted to visual function (Dutton 2006)

Two different pathways/ streams of vision

DORSAL STREAM

Spatial awareness, dealing with much visual information, control of visual guidance



VENTRAL STREAM

Visual recognition functions

Graphic from Vardit Kindler, OTR Israel

Dorsal stream dysfunction

Motor - spatial
Where is it?

- Difficulty seeing things that are pointed out in the distance.
- Difficulty seeing people/objects within a "visual clutter"
- Impaired movement through three dimensional space (optic ataxia)

Ventral Stream dysfunction

Perceptual
What is it?

- Impaired recognition of faces
- Impaired recognition of the language components of facial expression.
- Difficulty identifying shapes.
- Difficulty naming colors.
- Disorientation
- Poor visual memory

Dorsal stream damage:

Visual **motor** disturbances such as:
- moving the eyes to direct visual attention to an object,
- fixating on an object of interest,
- shifting fixation and gaze to a new visual stimulus,
- and accomplishing fine motor tasks such as copying a drawing

Visual **spatial** disturbances such as:
- localization of objects,
- judgment of direction and distance of objects,
- orienting the body in relation to the physical world (the "Where is it?" aspect of vision)

posterior parietal (occipital) lobe lesions

http://www.childrenshospital.org/az/Site2100/mainpageS2100P0.html

Ventral Stream damage:

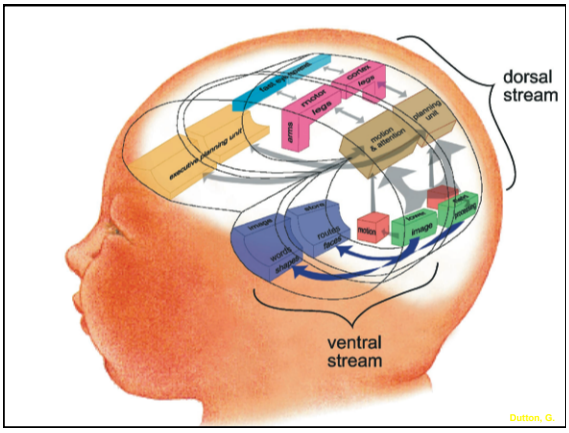
Visual **perceptual** disturbances such as:
- Difficulty with discrimination,
- Recognition (don't know familiar person until hear voice)
- and integration of visual images and objects (the "What is it?")

(inferior posterior temporal lobe lesions)

http://www.childrenshospital.org/az/Site2100/mainpageS2100P0.html

Most common missed diagnosis according to Dutton…

Lack of periventricular white matter (periventricular leukomalacia) can not only cause cerebral palsy *but it can cause visual problems in isolation*.



Prognosis

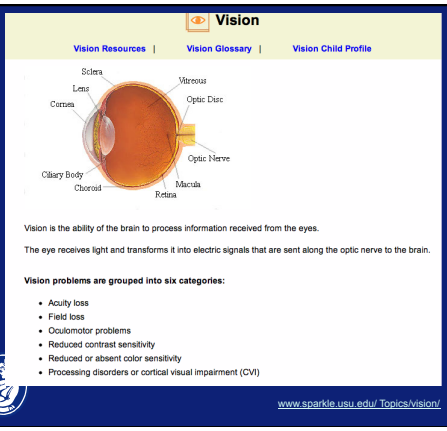
- Most patients with CVI will not regain normal vision. However improvement is usually seen over time. (Good, 2001)
- The prognosis is in correlation to the general neurological damage.

- The behavior of children with CVI is so characteristic that whoever is skilled in observing and detecting their visual behaviors, can save them from costly and invasive tests. The information that the parents provide is critical in the assessment process.

(Jan & Groenveld, 1993)

CVI should be considered when…

- Normal or near normal eye exam that can not explain the child's behavior
- A history or presence of neurological problems
- The presence of behavioral responses to visual stimuli that are unique to CVI
  - ****Child may have additional ocular impairments**



Characteristics of CVI

(Roman-Lantzy 2007)

OFTEN:

- Strong color preference, especially for red or yellow
- Need for movement to elicit or sustain attention (either viewer OR the object viewed needs to move)
- Visual latency (delayed response in looking)
- Visual field preferences
- Difficulty with visual complexity or sensory complex/competing information

Characteristics of CVI
(Roman-Lantzy 2007) continued

- Light gazing and non-purposeful gaze
- Difficulty with distance viewing absent of atypical visual reflexes
- Difficulty with visual novelty
- Absence of visually guided reach (can't look at and reach/touch an object at the same time)
- *** vision is not static and can change over time

My GOAL may be different from a vision specialist's goals/objectives:

- Primary goal is creating and expanding communication opportunities
- primary goal is **not** increased use of vision BUT we do want to encourage vision as an adjunct to being a more competent communicator

Typical inappropriate communication goals I see for children diagnosed with characteristics of CVI, complex motor and cognitive difficulty include:

- Student will identify requested object/photo/ symbol from a field of two
- Student will communicate a choice from a field of two objects/photos/symbols
- Student will match picture symbol to object

Patient photos or videos

Typical Progress Report Summary:

- Student inconsistently looks at options
- Students eye gaze is too quick/fleeting to interpret
- Student is too distractible to attend to task
- Student demonstrates maladaptive behavior when presented with communication choices
- Student does not consistently identify symbols suggesting poor comprehension of vocabulary

Why these outcomes?

- GOALS REQUIRE CHILD TO:
  - Visually attend/regard complete fiel
  - Visually track
  - Visually do a point-to-point shift
  - Visually confirm with joint attention to partner

Patient photos or videos

When no success:

Wait for a SPONTANEOUS COMBUSTION OF SKILL

Additional thoughts

- Communication is not 'choice making'
- 'COMMUNICATION' means that we don't already know what the person wants to say
- Some children are most interested in the social process, not the message

Patient photos or videos

Current Strategy #1:

Children are often asked direct questions with a right or wrong answer or given limited choices that don't go anywhere

"What is the weather?"

From Linda Burkhart

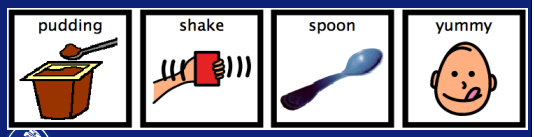
There is a Need for Children to Initiate and Carry-on a Conversation

Patient photos or videos

Gayle Porter of Australia with Young child and mother

Current Strategy #2:

Vocabulary flies in and out of thin air and then 'disappears' back into oblivion at the end of the activity.



From Linda Burkhart

Current Strategy #3

Children's options are limited to two or three objects as their performance is "inconsistent" or "hard to interpret".

Offered choices may not be what child really wants!

Costello 08

We need to present vocabulary that remains constant (does not disappear)
and is in a predictable location.

Current Strategy #4: "20 Questions"

We ask many questions based on what the partners *'thinks'* is important

Need a Way to Systematize "20 Questions" so the Child Can Begin to See a Pattern in How Vocabulary is Presented

Refer to Porter, G. PODD

Strategy: Partner Assisted Auditory - Visual Scanning

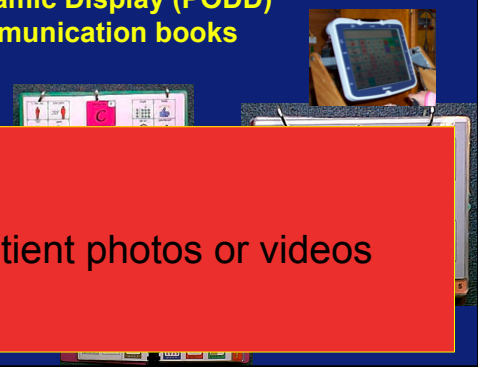
- Remove need to visually shift gaze
- Eliminate the need for communication success to b

Patient photos or videos

Strategy: Partner Assisted Auditory - Visual Scanning

- Supports expansion of language beyond nouns/objects
- Reduces random presentation of symbols that have to be consciously processed as new, each time.

Pragmatic Organization Dynamic Display (PODD) communication books



Patient photos or videos

Strategy: Partner Assisted Auditory - Visual Scanning

- Remove need to visually shift gaze
- Eliminate the need for communication success to be based on symbols
- Supports expansion of language beyond nouns/objects

*****I learned first from Linda Burkhart and Gayle Porter

considerations

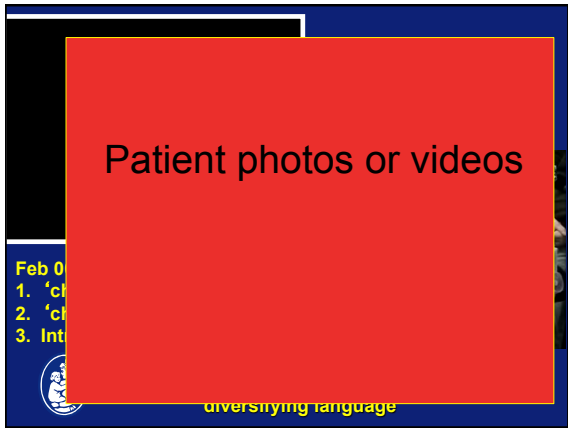
- Comprehension of spoken language
  - Only familiar?
  - Will attend to novel language?
  - Will learn after repeated consistent exposure?
- Responds affirmatively to all options
  - Does not yet understand 'confirmation' of choice?
  - Is more interested in the social connectedness and is excited by the process?
  - Is receptive to all options…really doesn't care?

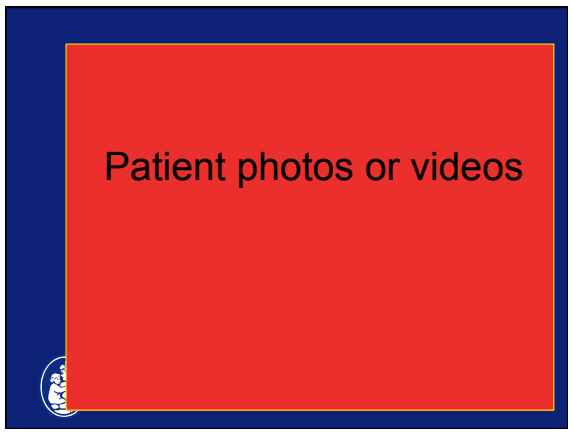
REMEMBER: DON'T EXPECT SOMEONE TO KNOW YOUR RULE WITHOUT INTENSE LEARNING OPPORTUNITY

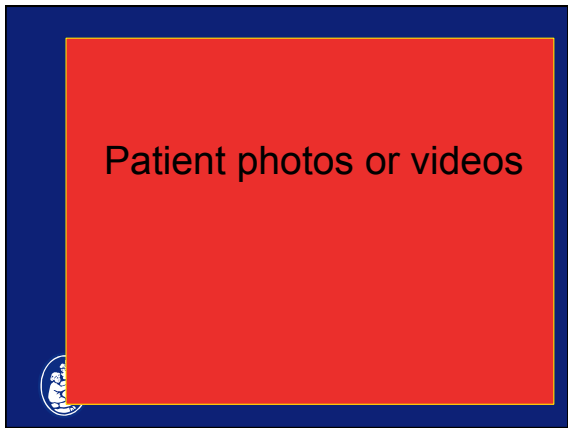
Video and material review

- Not elegant
- Part of a diagnostic session in which I focus on quickly assessing as many variables as possible
- In most instances, these videos represent the FIRST time child is introduced to this concept or an expanded feature of this concept.
- Otherwise, goals have been as previously described.

When watching each video… when you get concerned with the amount of time or the labor required, think about what the alternative is!


Patient photos or videos
Feb 0
1. 'ch
2. 'ch
3. Int
diversifying language


Patient photos or videos


Patient photos or videos

1. Strong Color Preference

- Unclear how or why attraction to a particular color evolves
- Possibly learned through repeated and consistent exposure
- 55% red; 34% yellow; 11 green, pink, blue (Pediatric View Study Lantzy and Roman 2002-2007)
- Roman discusses preferred color as 'visual anchor' for drawing attention

2. Difficulty with Visual Complexity

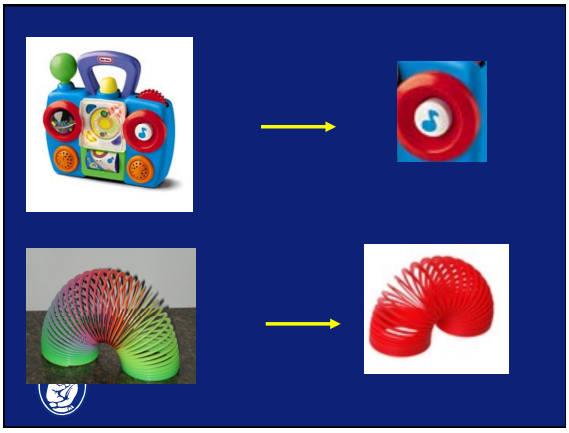
- **Complexity of visual field**
- **Complexity of visual symbols/patterns**
- **Complexity of visual plus auditory**

Complexity

- **Visual complexity compounds visual difficulties**
- **Complexity is one of the hardest characteristics to resolve**

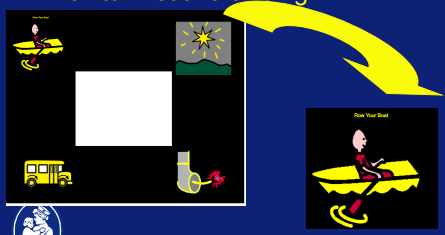
Complexity of Visual Field

Reduce Visual Complexity



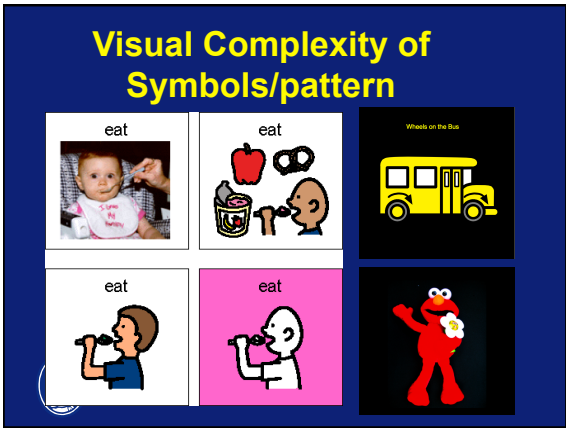
Complexity of visual array

- Monitor visual crowding

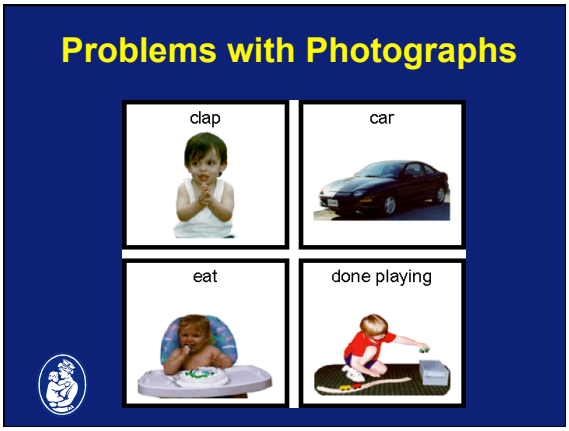


Patient photos or videos

Visual Complexity of Symbols/pattern

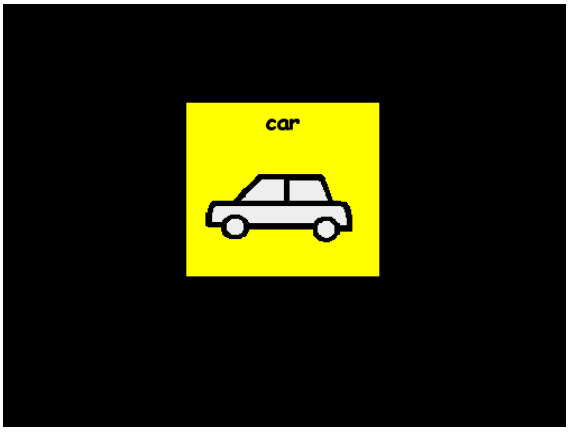


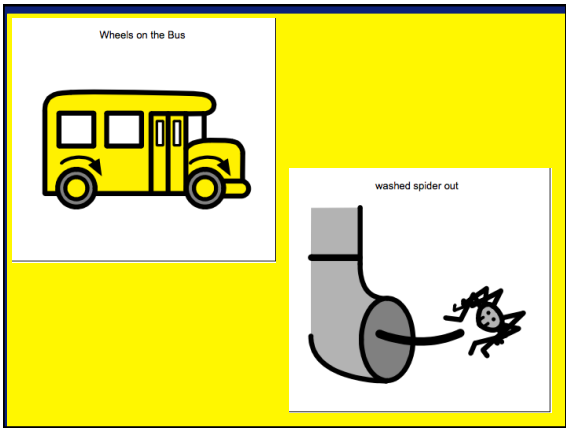
Problems with Photographs

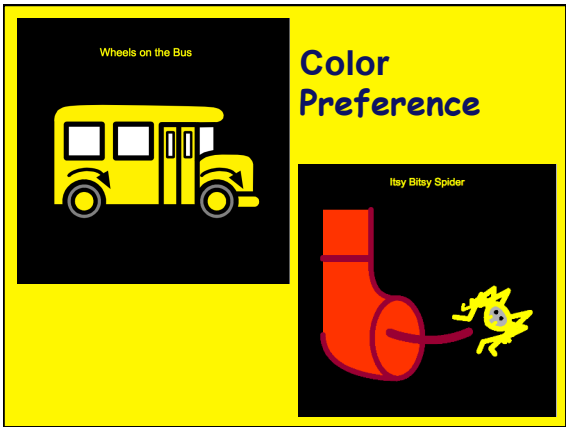


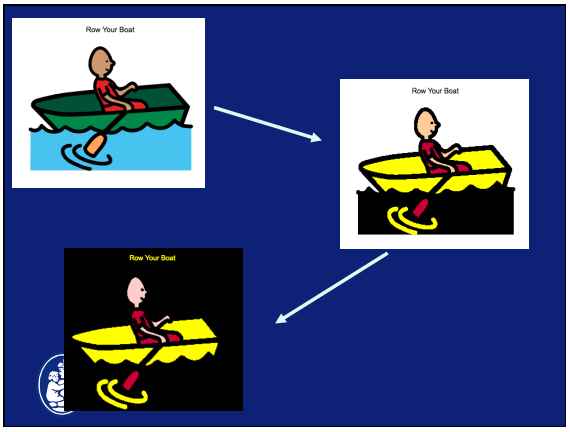

Yeah!
car
eat
all gone

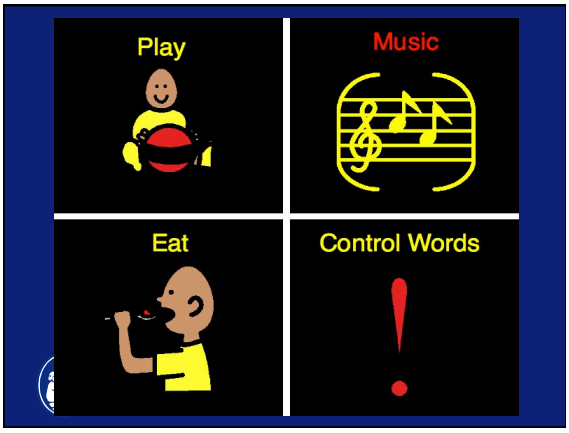

Yeah!
car
eat
all gone

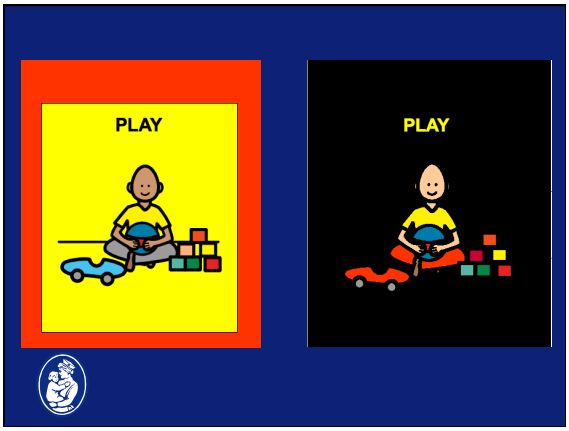

car


Wheels on the Bus
washed spider out

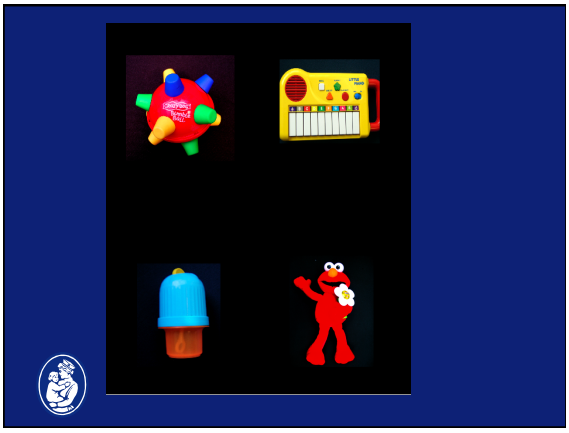

Wheels on the Bus
Color Preference
Itsy Bitsy Spider


Row Your Boat
Row Your Boat
Row Your Boat


Play
Music
Eat
Control Words
!


PLAY
PLAY


bumble ball
bubbles



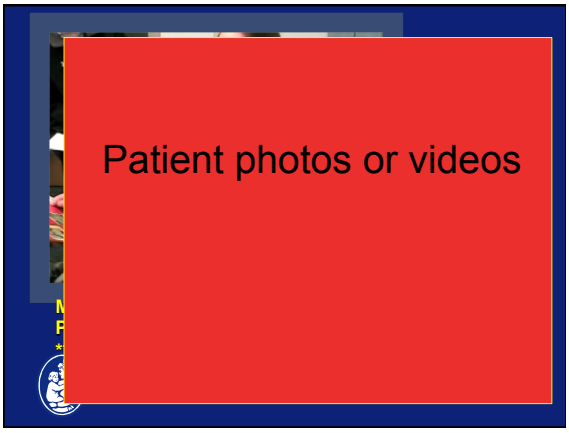
Patient photos or videos

Emphasizing contrast and reducing crowding .

Shiny lamination

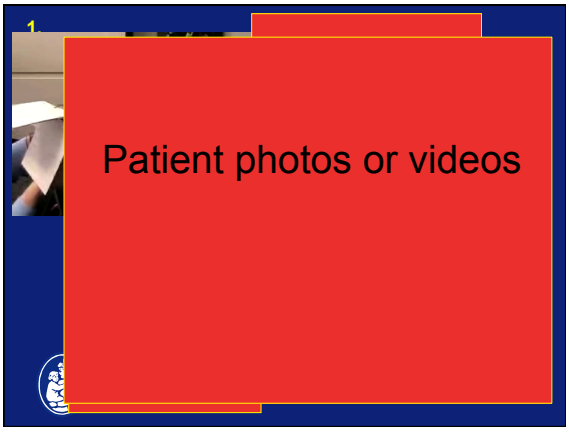
Matt lamination

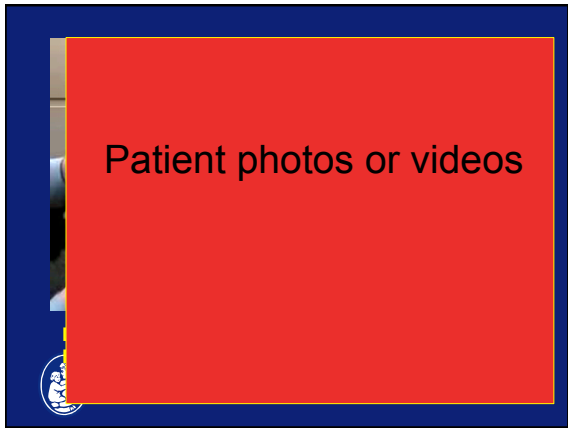
From L. Burkhart

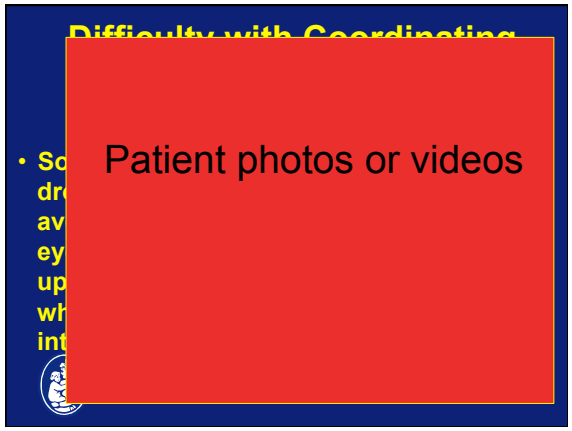


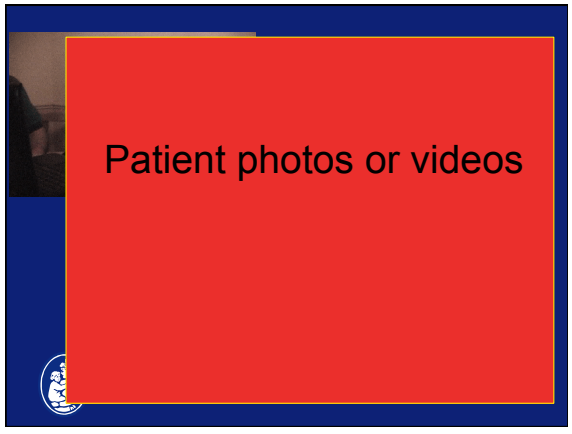
Complexity of sensory environment

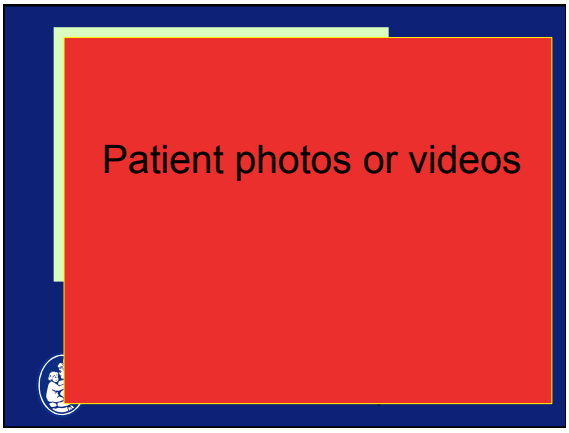
- For some, visual attention can occur ONLY when there is not competing sensory input.
  - may need to wait for child to stop visually regarding before giving verbal praise.
  - Minimize other movements, sound, etc. in room.
  - For many children 'vision will always lose' with competing sensory input.

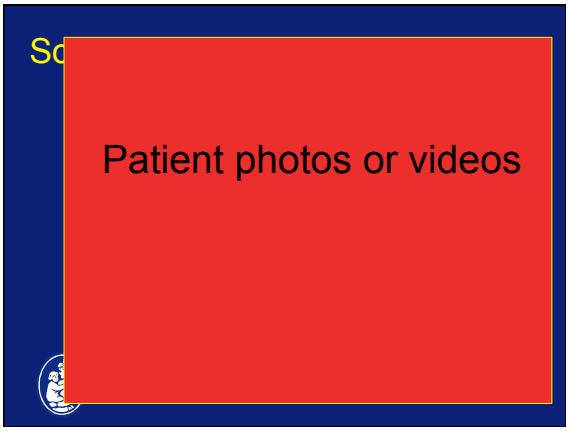



Patient photos or videos

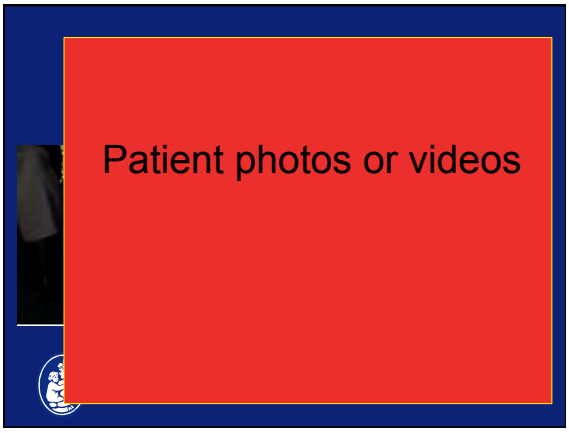

Patient photos or videos


Patient photos or videos

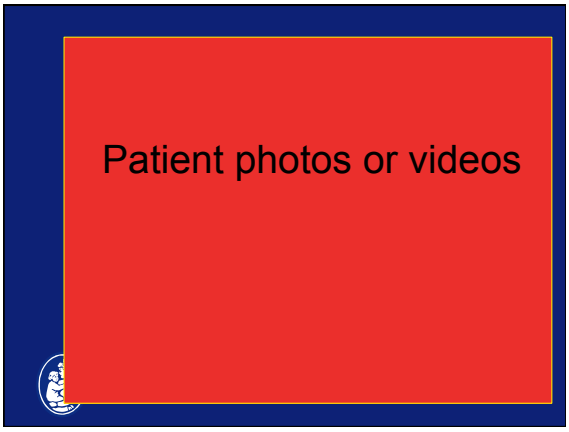

Patient photos or videos


Patient photos or videos


Some children use vision better when moving, rocking, swinging, moving head, etc.


Patient photos or videos

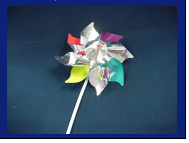

Patient photos or videos


Patient photos or videos

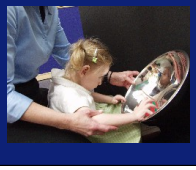
Patient photos or videos

3. Need for Movement

- Majority of children with CVI are attracted to objects with property of movement
- Many only see object when it is in movement OR when they themselves are in movement (swaying head, move in chair, look out



- Preference for objects with reflective properties (shiny/glittery).
- Perceived in the brain as movement. (Roman,2007)



Some children see better

Patient photos or videos

Shake Picture Symbol in Peripheral Visual Field - Then, Move Toward Central Field

slig

Patient photos or videos

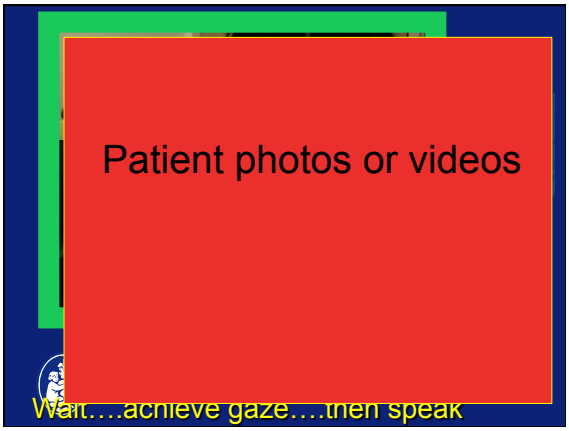
Patient photos or videos

Communication Intervention

- Slight movement of objects or symbols being presented
- Closely observe head and eye movement and impact on visual attention and participation.

4. Visual latency

- Delayed response in looking from time target is presented to when item is visually regarded. (seen in children with minimal amounts of consistent vision)
- Other impact of latency include fatigue, over stimulation or minimal practice time



Intervention for communication

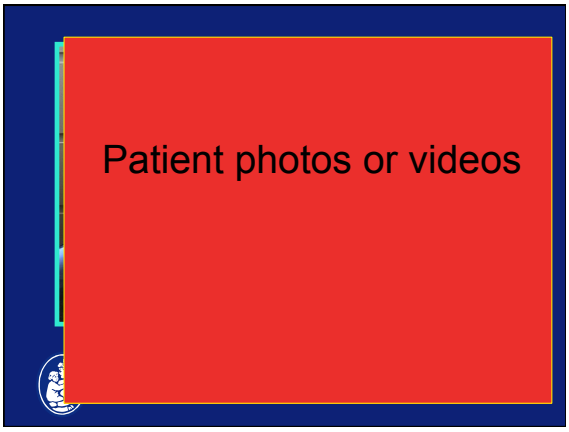
- Allow plenty of time (varies by person)
- May not always require visual attention to communicate
- Minimize competing sensory input as 'vision will always lose'

5. Visual Field Preference

- Present in almost all students who have CVI (Jan and Groenveld 1993)
- Many may have peripheral field preference (peripheral vision regulates:
  - seeing in low light,
  - perception of moving targets and
  - ability to perceive forms in space

Visual Field Preference (cont'd)

- Many show a mixed field preference by eye (may notice position of object with one eye, then turn head to exam object with other eye)
  - It is rare that central vision is preferred for children with CVI



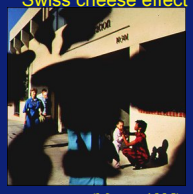
Visual Field Differences

- children show a variety of differences in visual fields
- May change - improve and worsen
- May be like "Swiss Cheese"

- Do not scan the environment.
- Rely on peripheral vision due to visual field loss.

Central Scotoma

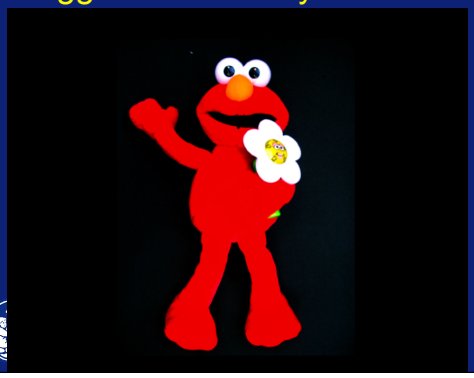
Swiss cheese effect

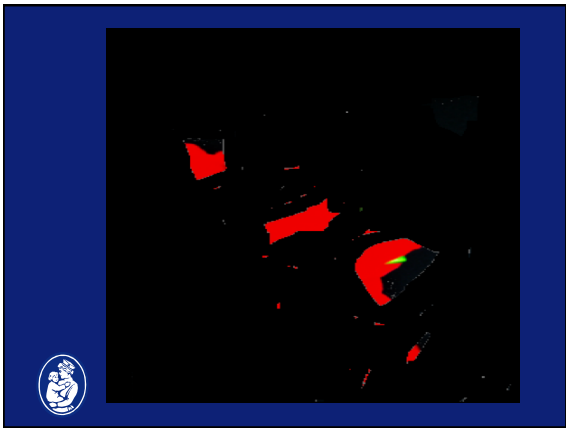


(Moore, 1995)

Kindler, V. 2008

Bigger is not always better!





Exercise – need volunteers!

"When a child with CVI needs to control his head, use his vision, and perform fine motor tasks, the effort can be compared to a neurologically intact adult learning to knit while walking a tightrope."

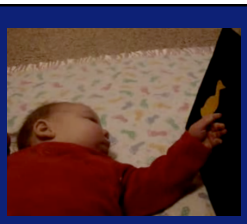
– http://www.tsbvi.edu/outreach/seehear/fall98/cortical.htm

Intervention

- Note where a child will attend to objects and pictures at any given time and make appropriate adjustments
- Recognize that 'looking' is not always done in a standard manner. Encouraging child to have head and eyes forward may actually sabotage the child's success.
- Communication supports must be versatile enough to continue, even when vision cannot be successfully engaged and suit the dynamic nature of useable vision.

Considerations:

- Use light to highlight objects/symbol.
- Minimize other competing light in the environment
- computer may be used to attract visual attention
- Don't demand eye contact.



From: Erin Kane's CVI Journal
YouTube

6. Light gazing and non-purposeful gaze

- May gaze (and be attracted to) light from window or light from overhead light
- May be used as a strategy to avoid overly confusing/overwhelming visual array.
- Some students can not look and listen simultaneously, thus will look away from target toward a blank wall or light when listening

- Light gazing

Patient photos or videos

Difficulty maintaining the

Patient photos or videos

Patient photos or videos

7. Difficulty with Distance Viewing

- Related to complexity of the environment.
- The more complex, the more difficult it is to identify an item
- Student may see something at a great distance IF there is minimal visual compexity/crowding.

Possible intervention consideration:

Bring pictures close for attention, bring back for focus

8. Difficulty with visual novelty

- Child may attend to familiar patterns only
- New items may be ignored OR child may respond with great agitation/fear to novel items

- **Build a repertoire for communication by using functional objects and symbols that are *meaningful* to the child.**
- **Provide repeated and consistent/predictable opportunities to learn new visual information by pairing a visual with the activity. Make it part of the routine and ideally pair it with something that is already familiar.**

9. Absence of visually guided reach

- Looking and reaching appear as two separate events (may look, then look away, then touch)
- Often is misinterpreted
  - "look before you touch"
  - "you have to look at what you are touching"
  - "she didn't mean that because she wasn't even looking"

So…..I've demonstrated a lot of partner-assisted auditory/visual scanning

- **Why partner assisted Auditory - Visual Scan?**

- A consistent approach-
  - Language is delivered using the same approach across communication partners and is presented in a regular order using consistent language.
- Eliminates need to shift eye gaze-
  - Many individuals (especially those with cortical visual impairment) have difficulty shifting their eye gaze from one place to another to visually regard options (i.e., when several items are simultaneously placed on a display board).
- Capitalizes on strong auditory skills, while still encouraging the use of vision.

- Communication becomes more predictable-
  - With frequent exposure to the same information, the individual has the opportunity to become familiar with both the vocabulary and representation used during scanning.
- Paces the partner and reduces language load presented to the individual
- Eliminates the need for communication success to be based on visual symbols
- Supports expansion of language beyond nouns/objects and choice making (e.g. "I like this!" or "That's funny!").

Assessment

- "**Our lives teach us who we are**"
  - **Salman Rushdie**

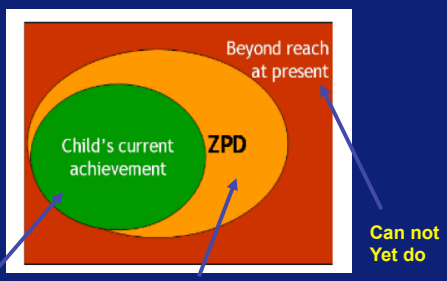
Remember…

- Due to the complexity of their needs, children with CVI may not spontaneously develop the early communication behaviors that we generally rely on to inform our practice.
- BE CAREFUL! DO NOT wait (and wait) for a "spontaneous combustion of skill"!

Past experience

Vygotsky (1978) argued that assessments where the examiner does not actively intervene provides data on the child's past history and present functioning, but NOT on the child's potential for learning.

"the 'zone of proximal development', where children develop language by solving communicative challenges with the help of more competent members of their language environment." Renner, 2003 p 82



ATHERTON J S (2005) Learning and Teaching: Constructivism in learning. [On-line] UK: Available: http://www.learningandteaching.info/learning/constructivism.htm Accessed: 13 July 2008

Multiple skills in every task (Porter, 2008)

- Sensory
  - See, hear, feel the materials
  - Feedback to move body
- Motor
  - Facial expression, body movements, looking, pointing, gesture, activating a switch, speech, etc.
- Cognitive
- Social-emotional
- Communication

What are we assessing?

Because of the lack of clear feedback or response from the child:

- Partners may edit their interactions
- Provide minimal language learning opportunities
- Fear that 'more is too much' and 'less is instructional'
- Thus minimizing the rich language learning environment

Aided Language learning opportunities

"The attitudes and expectations of people in the environment may to some extent influence all children's language development, but they may be critical for children who use alternative forms because these children depend on the means and opportunities provided by professionals."

von Tetzchner & Grove, 2003 p.15

Several parents have told me that they thought successful expressive language must 'mean something' to you or be contextually related

- Think of typically developing children who randomly talk…sometimes it is evident that their objective is to simply 'have the floor' and they have little interest in the form or content of the message

If we have time….

Frequently Asked Questions

He can't choose between two items consistently. How could he be ready for more language?

Frequently Asked Questions

He doesn't have a consistent and reliable yes/ no. Shouldn't we establish that prerequisite first?

Frequently Asked Questions

It looks like she is not even paying attention when we model. Doesn't she need better attention skills first?

Frequently Asked Questions

Shouldn't she demonstrate consistency with objects before we use two dimensional representations?

Learning to Understand the Child's Communication

Golden rule: In the beginning, the responsibility is YOURS

- Be a good observer
- Provide commentary to what you see
- Consistently respond to behaviors
- Engineer success when the child can not do it herself.

Remember:

We CO-construct communication with typical early language learners, why wouldn't the child with complex needs require the same thing?

Who makes the rule?

- The child's goals of communication may not be what YOU think they should be.
- Respect the child's agenda, and she'll learn to respect yours

Possible agenda

- I just want you to interact with me
- I'll know what I mean to say once you help me say it!
- Let's explore together
- I want the 'use' - I don't care about form or content!

Possible agenda (continued)

- I am not interested in saying "I have to go to the bathroom"….so I will not pay attention to your instruction
- I AM interested in saying "It is yucky" (because I like your reaction) and I WILL pay attention to that!

Take Home:

- **Children with CVI require consistent and predictable opportunities to experience and manipulate language.**
- **Language exposure and success should be built upon - but not dependent on - engaging vision.**