Augmentative Communication Program
- Outpatient (Waltham campus)
- Inpatient (Longwood campus)
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

Interesting fact:

- Cortical Visual Impairment is the #1 incidence of visual impairment in first world countries due to high level of intensive care and quality of medical intervention.
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”


Guiding principles of CVI

Christine Roman-Lantzy, Ph.D. & Sarah W. Blackstone, Ph.D., CCC-SP
AAC By the Bay, March 1, 2014

• CVI is fundamentally different than ocular causes of visual impairment
• Children with CVI require specialized methods for identification, assessment, and intervention
• Functional vision improvements are facilitated, not automatic (intervention is the key)
• No child is too brain injured to see

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
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)

<table>
<thead>
<tr>
<th>ACQUIRED CF</th>
<th>CAUSES OF BRAIN DAMAGE</th>
</tr>
</thead>
<tbody>
<tr>
<td>Acquired injury</td>
<td>e.g., head injury, car accident</td>
</tr>
<tr>
<td>Seizure disorder</td>
<td>e.g., epilepsy, migraine</td>
</tr>
<tr>
<td>Head injury</td>
<td>e.g., concussion, contusion</td>
</tr>
<tr>
<td>Stroke</td>
<td>e.g., cerebral hemorrhage, ischemic stroke</td>
</tr>
<tr>
<td>Trauma</td>
<td>e.g., gunshot wound, blast injury</td>
</tr>
<tr>
<td>Infection</td>
<td>e.g., meningitis, encephalitis</td>
</tr>
<tr>
<td>Tumor</td>
<td>e.g., glioma, meningioma</td>
</tr>
<tr>
<td>Medication</td>
<td>e.g., neuroleptics, chemotherapy</td>
</tr>
</tbody>
</table>

From Roman-Lantzy & Blackstone, 2014 (in preparation)
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
**DORSAL –** The peripheral vision that helps differentiate where things begin and end
- handling the complexity of the visual scene

**VENTRAL –** the ‘what is it’ or development of acuity in the brain
- difficulty with recognition

<table>
<thead>
<tr>
<th>Dorsal stream dysfunction</th>
<th>Ventral Stream dysfunction</th>
</tr>
</thead>
<tbody>
<tr>
<td>Motor - spatial</td>
<td>Perceptual</td>
</tr>
<tr>
<td>What is it?</td>
<td>What is it?</td>
</tr>
<tr>
<td>- Difficulty seeing things that are pointed out in the distance.</td>
<td>- Impaired recognition of faces</td>
</tr>
<tr>
<td>- Difficulty seeing people/objects within a &quot;visual clutter&quot;</td>
<td>- Impaired recognition of the language components of facial expression</td>
</tr>
<tr>
<td>- Impaired movement through three dimensional space (optic ataxia)</td>
<td>- Difficulty identifying shapes</td>
</tr>
<tr>
<td></td>
<td>- Difficulty naming colors</td>
</tr>
<tr>
<td></td>
<td>- Disorientation</td>
</tr>
<tr>
<td></td>
<td>- Poor visual memory</td>
</tr>
</tbody>
</table>

**Dorsal stream damage:**
- difficulty handling the complexity of the visual scene
  - can’t find toy in a toy box
  - can’t find clothing in a drawer or a pile
  - seeing a distant object (because there is so much to see)

Finding someone in a group
Getting lost in crowded places
Reading
Difficulty with visual guidance of movement
  - difficulty with reach and grasp
Difficulty walking over uneven group and steps, even though viewing directly and has good motor function
Difficulty ‘dual tasking’
  - bumping into obstacles while talking and walking

Dutton, Developmental Medicine & Child Neurology 2008
Ventral Stream damage:

Difficulty with recognition
- recognizing people and knowing who is unknown
- understanding the language of facial expression
- recognizing shapes and objects and their alignment

Difficulty with orientation
- navigating inside the house
- navigating outside the house

Dutton, Developmental Medicine & Child Neurology 2008

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 & Groenfeld, 1993)
CVI is likely when:

- Eye exam does not explain visual behavior (eye looks fine but child does not use vision to look at item or faces, etc.)
- There is a history of neurological event
- Person demonstrates the ten behaviors of 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
• Absent or atypical Visual reflex
• 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

So, what do we know?
• Vision, language, learning, mobility, and communication are developmentally interconnected
• Children with CVI and CCN require an integrated, dynamic, early intervention approach that specifically addresses their development, their participation and their ability to function in the world.
• No child with CVI and CCN should be denied access to language, learning, communication and full participation.
• Access to language (and sufficiently large vocabularies) is essential to the long-term cognitive, educational, social and communication development of children with CCN.
• The nature of the language input that children with CVI receive may assist them to interpret what they are seeing, thus it should be addressed mindfully.
• Vision, language, learning, communication and participation goals can, and must be considered concurrently, even if, and when, they are not addressed simultaneously.

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

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 field
  - Visually track
  - Visually do a point-to-point shift
  - Visually confirm with joint attention to partner

When no success:

- Identified as not appropriate ‘yet’ for communication services
- Wait until child has ‘developed’ prerequisite skills
- In other words... Wait for a SPONTANEOUS COMBUSTION OF SKILL

Additional thoughts

- Communication is not ‘choice making’
- Nobody will sustain communication if they have to work at it (think of how exhausting talking in English is!)
- ‘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
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?”

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

Current Strategy #2:
Vocabulary flies in and out of thin air and then ‘disappears’ back into oblivion at the end of the activity.
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!

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 be based on symbol recognition

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

Communication can be story telling...
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

Some things to consider when introducing language through AAC

- 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!
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
“I don’t say visual discrimination….I say visual complexity”

Complexity

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

Complexity of Visual Field
Reduce Complexity
Reduce Visual Complexity

Costello, J.M.   Children's Hospital
Boston © 2014
Complexity of visual array

- Monitor visual crowding

Visual Complexity of Symbols/pattern

- Eat
- Eat
- Elmo
- Happy Meal

- Eat
- Eat
- Eat
- Eat

- Eat
Emphasizing contrast and reducing crowding.
Shiny lamination  Matt lamination

Visual From L. Burkhart
Mom’s thought on color contrasts
Performance with yellow and red vs. white background

**We had not been told Ellie had a diagnosis of CVI!!**

**Ellie**

**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.

**CLINICAL BLOOPER:**

1. **QUIET … THEN SPEAK**
Difficulty looking and listening but still benefits from the language exposure/modeling/opportunity

Difficulties with Coordinating Looking and Listening

- Some children drop their heads, avert gaze, close eyes or roll eyes up to block vision when listening intently

Visual attention:
- Without verbal "place setter"
- With verbal place setter
Some children use vision better in certain positions

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

Use Movement, Light and ‘organized sound’
Pay attention to where a child will attend to objects and pictures at any given time and make appropriate adjustments

(Video - Leah)

Seamus - accommodate his positioning

Elizabeth – notice head movement to support vision
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).

Some children see better when they are moving – rocking, swinging, riding in a vehicle.

- Preference for objects with reflective properties (shiny/glittery).
- Perceived in the brain as movement.
  (Roman, 2007)
Shake Picture Symbol in Peripheral Visual Field - Then, Move Toward Central Field

Slight head movement and eye movement. Note his minimal ‘looking’ behavior but think of lost language opportunity without using PPAVS.

Johnny

Coordinate reach with computer scan.
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

Field preference

• Many have difficulty with lower fields.
  - If independently mobile may be considered ‘behavioral’ in some environments.
  - In reality, may not be able to see and perceive, thus are resistant

Intervention: modify environment

As seen in Perkins School CVI video
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.

(Moore, 1995)
Kindler, V. 2008
Bigger is not always better!
Exercise – need three 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.

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

Difficulty maintaining the ‘look’

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 complexity/crowding.
Possible intervention consideration:

Bring pictures close for Attention to details, 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
**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 of the child**

- 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!
Frequently Asked Questions

I already know what he wants to tell me - why do I need Partner assist scanning?

Taking points:
• Do you really already know what he wants, or has he learned to only tell you what you can figure out?
• If he has never experienced access to more language, how can he possibly demonstrate that he does or does not need it?

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?

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.