#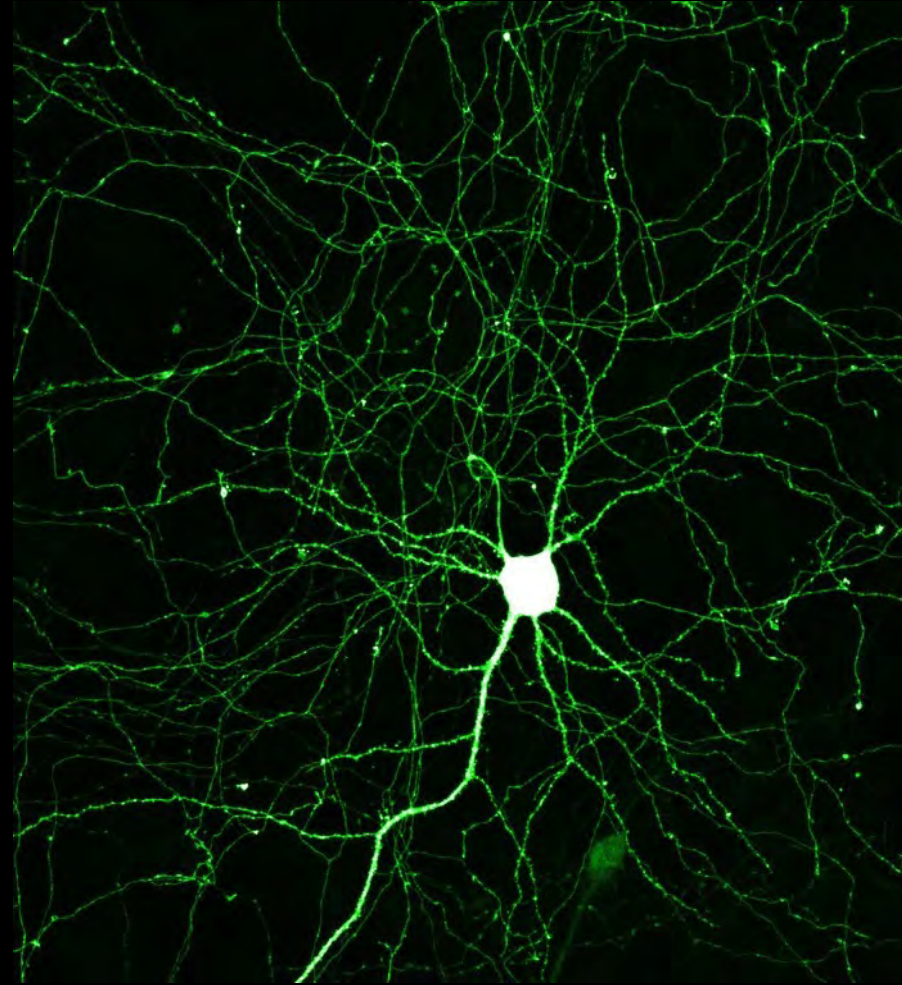 Supporting Availability for Learning for Children with Visual Impairments and Complex Care Needs

CA AER Conference 2024
Chris Russell, MS. Ed., TVI
Christopher.russell2013@gmail.com

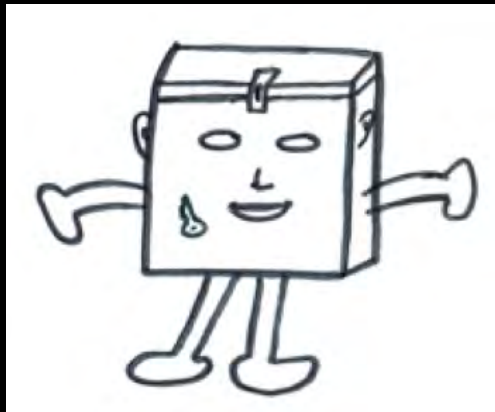# Contexts: Children with Visual Impairments & Complex Care Needs

- Wide range of communication modalities and levels of expressive communication
- Wide range of visual/tactile/auditory access and adaptive needs
- Sensory balance & need for input – vestibular, proprioceptive

Internal/medical considerations affecting availability for learning & biophysical equilibrium

"The Box of DeafBlindness"

The Box of Deafblindness™
A Visual Framework for Facilitating Engaged Learning
Kimberly Lauger, Nov. 2012

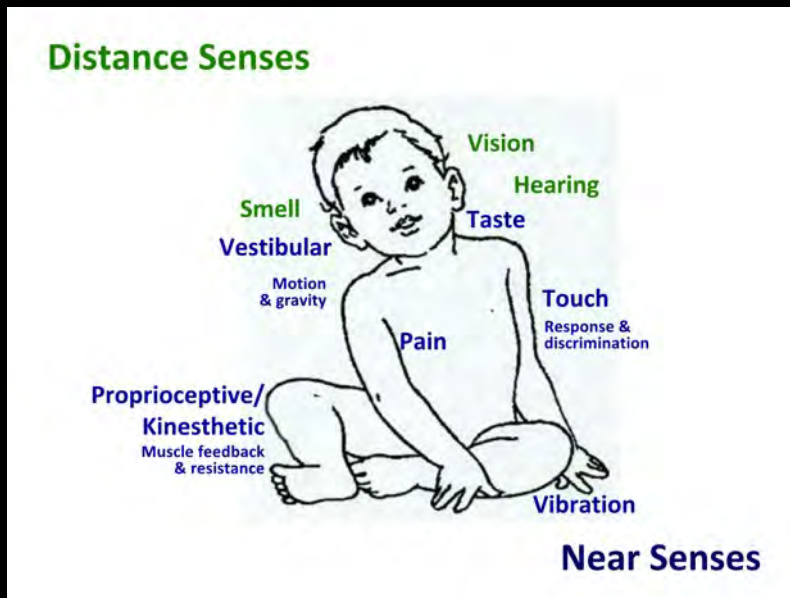https://www.youtube.com/watch?v=LTUgmCjb4s4

- What goes into your child's "box" of sensory experience?
  - Understanding etiology and history

- What are your child's residual senses (windows)?

- What pulls the child out (the key)?

- What makes the child retreat?

Kimberly Lauger, 2012, from NCDB OHOA Intervener Module 2

Visual impairment / sensory impairments are disabilities of access…

Distance Senses

Vision
Hearing
Smell
Taste
Vestibular
Motion & gravity
Touch
Response & discrimination
Pain
Proprioceptive/ Kinesthetic
Muscle feedback & resistance
Vibration

Near Senses

90% of information is received through our distance senses: vision and hearing

- If a child cannot clearly see or hear what is going on around them they will miss:

  - Motivation to move & explore
  - Knowing who is with them
  - Social cues and contexts
  - Concepts: environmental, objects, interpersonal, intrapersonal

Concept Development

- How the world works: routines, what things are used for, cause-and-effect

- How the physical environment is arranged and how to navigate it (O&M)

- Where things come from (the natural world and its cycles and laws)

- How things are sequenced (time, order of activities)

- Self-concepts

- Social concepts

Miles & McLetchie, 2008

Understanding functional vision…

VisionSim app, The Braille Institute

Ocular visual impairment or CVI?
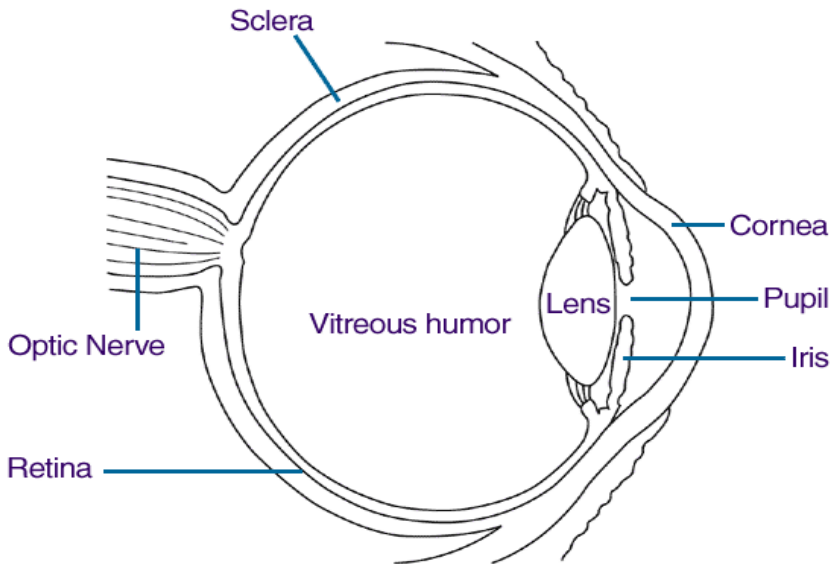
- Acuity loss vs complexity
- Field loss vs preferences
- Contrast vs color & complexity

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

Cortical Visual Impairment (CVI)
A Fact Sheet for Families & Professionals

What is CVI? Cortical visual impairment (CVI) is a neurological form of visual impairment caused by "damage or atypical structures in the visual pathways and/or visual processing centers of the brain" (Roman Lantzy, 2018). CVI is the leading cause of visual impairment in children in countries or regions with access to quality neonatal health care.

How is it different from other visual impairments?

Individuals with CVI often have healthy eyes and obtain normal results on an eye exam, because it is the processing of vision in the brain that is atypical. CVI does not have an impact on visual acuity, contrast sensitivity, or many of the other symptoms of ocular visual impairments. CVI cannot be corrected with glasses.

Children and youth with CVI can be **expected** to make progress in their visual functioning over time if provided with appropriate assessment and intervention. CVI requires a very different approach to instructional supports and environmental/material adaptations as compared with ocular visual impairments.

How is CVI diagnosed? *There are 3 criteria for diagnosing cortical visual impairment:*

- **History of neurological impact,** abnormal development, damage or trauma (the most common causes are anoxic brain injury associated with premature birth or other TBI [hypoxic ischemic encephalopathy, periventricular leukomalacia, stroke or seizure]). CVI can also be associated with genetic syndromes such as AGS, CDKL5, etc.)
- **Abnormal visual behaviors that cannot be explained by the clinical eye exam**
- **The presence of unique visual Characteristics associated with CVI:**

10 Characteristics are associated with CVI, and each will look different depending on where the individual's visual processing falls on a range of visual functioning (**The CVI Range** [Roman, 2007; Revised Edition, 2018]):

○ Color preferences (often red, yellow, saturated)	○ Difficulty with distance viewing
○ Need for movement (to elicit/sustain attention)	○ Atypical visual reflexes
○ Visual latency (processing time)	(blink to touch, blink to threat)
○ Visual field preferences	○ Difficulty with visual novelty
○ Difficulty with visual complexity	(easier with familiar objects, people, settings)
(array, target/object, multisensory, faces)	○ Difficulty with visually guided reach
○ Need for/attraction to light	(looking and reaching/touching at the same time)

Visual functioning in CVI is measured across the CVI Range (0-10), with three major phases describing level of impact of the CVI Characteristics on the individual's ability to use her vision functionally:

- 0-3   Phase I   Most severe impact on visual functioning
- 3-7   Phase II   Moderate impact on visual functioning
- 7-10   Phase III   Closest to typical visual functioning

It is important to identify a child's specific visual functioning on the CVI Range with regard to each characteristic, as **the intervention approaches needed to support progress in visual functioning are unique to each Phase.**

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:

- o   Pediatric Cortical Visual Impairment Society family advocacy group with extensive resources on CVI
- o   "Statement on Cortical Visual Impairment" (Roman, Baker-Nobles, Dutton, Evans Luiselli, Flener, Jan, Lantzy, Matsuba, Mayer, Newcomb, & Nielsen, 2008)
- o   Roman on CVI YouTube Channel for a variety of short videos for families and professionals on CVI topics
- o   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
- o   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)
- o   *Professional development opportunities*:
- •   Perkins E-Learning online classes on a variety of topics related to CVI

Complex Health Care Needs is a broad term

Other Health Impairments (IDEA):
"having limited strength, vitality, or alertness, including a *heightened alertness* to environmental stimuli that *results in limited alertness* with respect to the educational environment." (Selekman, 2017)
- Includes asthma, type 1 diabetes, ADHD, etc.

Unique conditions
→ *unique impacts and support needs*

CHARGE Syndrome – Focus on Proprioception

- Differences in proprioception because of
  - Lower muscle tone – less information getting through proprioceptive sensors (in joints)
  - Visual impairments – "motivation to resist gravity"
  - Other life experiences – time in hospital, etc.

- Deep pressure is *calming*, light touch is *stimulating/arousing*
  - COMPRESSION, STRETCHING, TWISTING

David Brown, 2014. "CHARGE Syndrome & Sensory Processing" (Perkins eLearning): https://www.youtube.com/watch?v=KYwSpxpPgxI

What do you have to open the box?

- Relationships

  Attachment, security

- Communication

- Sensory access

- Environmental supports

  How can the environment or setting be modified or altered to support sensory input?
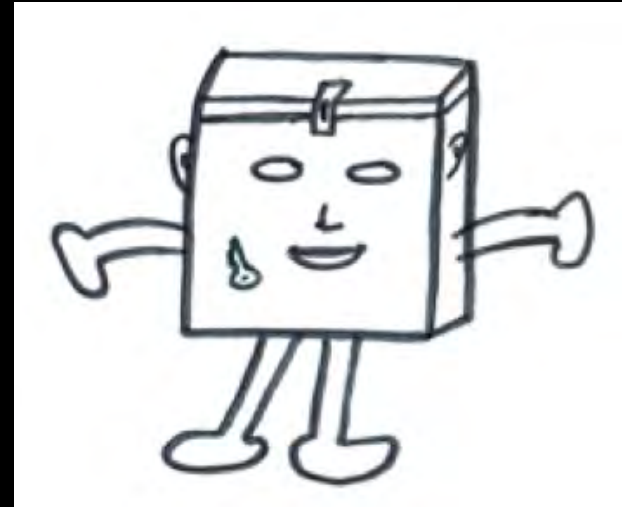
Availability for Learning

How do you know if your child is *available for learning*?

■How can you tell that the child is:

- Alert?

- Attending?

- Responsive or responding?

- Processing information?

- Retaining information?

What *is* learning?

Learning is physical change in the brain.
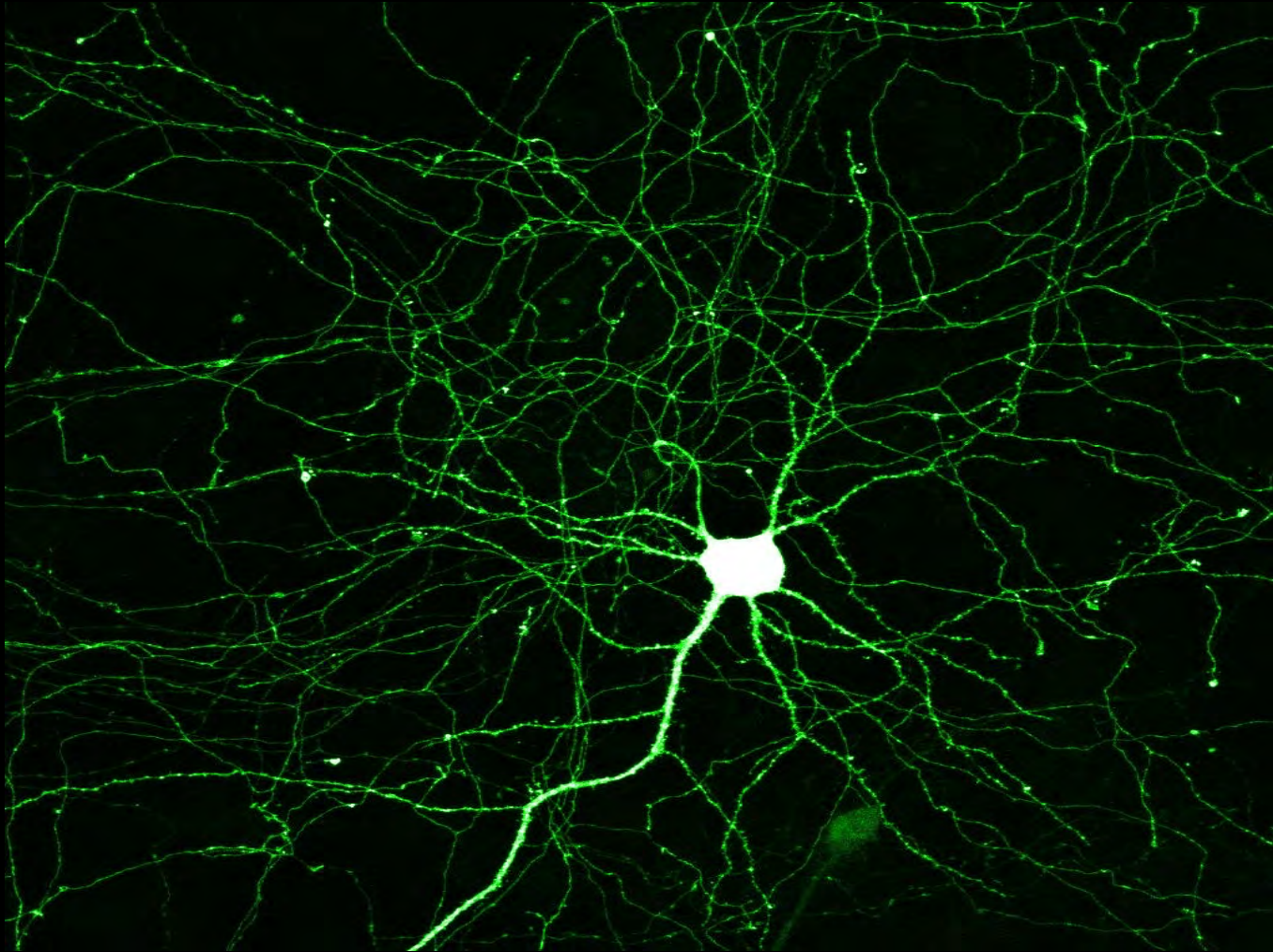
(Slide from Susan Edelman, 2015)

How do you know if your child is learning?

- **Habituation** – getting used to something
  - Eg something that used to make you startle, or be distracted, but now you don't notice it

- **Association** – spoon and pudding example

- **Anticipation** – shift in state given a cue

- **Surprise** – "a mismatch in expectations"

(Robbie Blaha, TSBVI)

Orienting Reflex

- "A reflexive alerting to significant things"
- Shift in state
  - Agitated to calm, drowsy to alert

- NOT the same as "defensive startle"

- What does it look like for each child?
- Involve the family in identifying
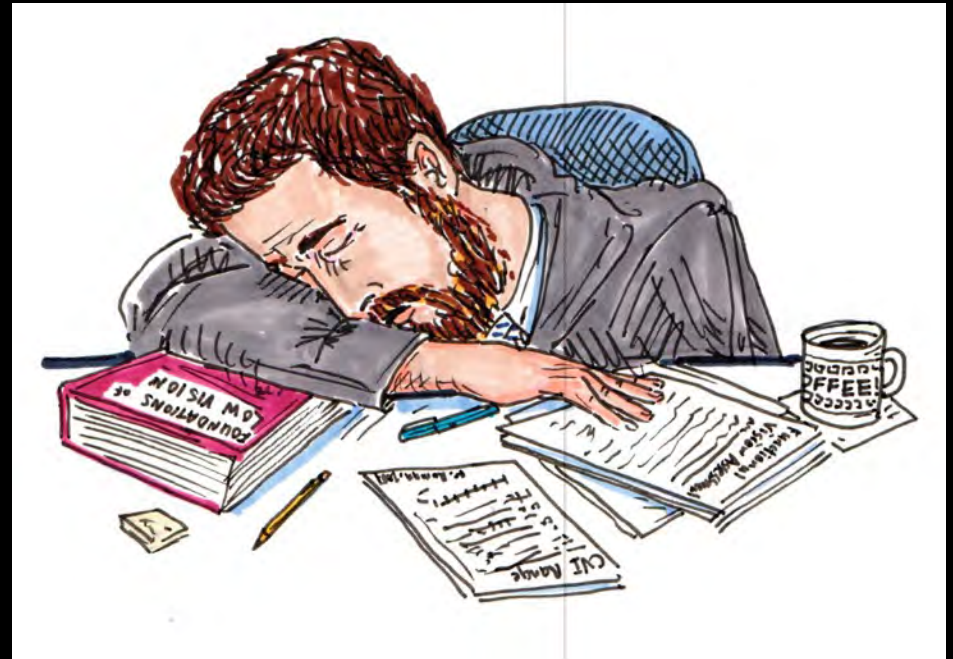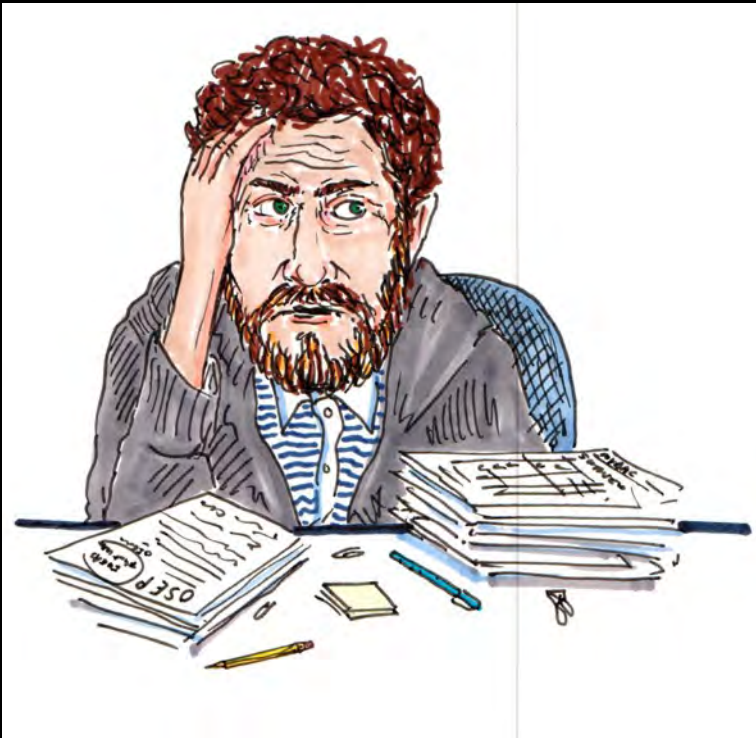
(Blaha et al., TSBVI; Nelson et al., 2002)

When are we *NOT* learning?

Bio Behavioral States:

Carolina Record of Individual
    Behavior

- Deep sleep
- Intermediate sleep
- Active sleep
- Drowsy
- **Quiet awake**
- **Active awake**
- Fussy awake
- Mildly agitated
- Uncontrollably
Agitated

D. Guess et al 1988, 1993

- Sleep States
  - Inactive
  - Active
- Indeterminate States
  - Drowsy
  - Daze
- **Preferred awake state**
  - **Inactive alert**
  - **Active alert**
- Other awake States
  - Awake active Stereotypic
  - Crying agitated

Video Example –
Pre-intentional communication / orienting reflex

- What is the student's orienting reflex to attend/calm?

- What prompted the child's orienting reflex?

Children with Limited/No Motor Control

What do:

- Pre-intentional behaviors / reflexes
- Temperature
- Heart-rate
- Breathing pattern

    …tell us about availability for learning?

Pre-intentional Goals?

Given a light touch on the shoulder, and shown the concrete symbol for a new activity, then given the verbal prompt "It's time for _____ (activity)" and 10 seconds processing time before any additional prompting, Sarah will demonstrate increased anticipation to show understanding of the transition between activities by reducing the elevation of her heart rate and breathing (*specific measurements?*).

Prompt Hierarchy

Least Intrusive
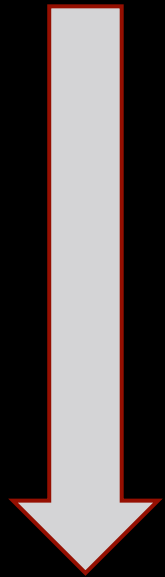
Most Intrusive

- Wait for response
- Gesture, pointing (finger, flashlight, auditory cue to localize/tapping, hand-under-hand pointing)
- Verbal or tactile (signed) prompt, touch cue
  - Note levels of VP
- Visual modeling, hand-under-hand modeling
- Hand-under-hand instruction
- Hand-over-hand instruction / coactive shaping

Hand-under-hand approach

- is non-controlling.
- allows the child to know that you share the experience of touching the same object or of making the same kind of movements.
- does not obstruct the most important parts of the child's own experience of any object he may be touching.

"Talking the Language of the Hands to the Hands" by Barbara Miles, M.Ed.
http://www.nationaldb.org/documents/products/hands.pdf

Mutual Tactile Exploration

Processing ("wait") time

"One or two minutes sounds like a relatively short period of time, but when you are waiting for a child to act on a request, it can seem like an eternity."

- Belote, 2005

Touch Cues

- A touch at a specific place on a student's body that is done consistently to convey information about an upcoming event

- Provide information, express wants/needs, give a directive, give feedback

- Concrete referent for sign when paired

- NOT meaningless prodding, prompting, or tapping

Examples of Touch Cues

- **Hello** Touch hand, shoulder or back.

- **Sit** Gentle pressure on shoulder, feel chair

- **Stand** Gentle upward pressure to elbow

- **Eat/Drink** Touch their fingers to their lips

- **Toileting** Gently tap side/hip

- **Hand washing** Rub their hands together gently

- **Picking up from lying position** Tap or gently lift shoulders

- **On/off ankle orthotics** Light touch on shin

- **On/off glasses or cochlear** Light touch on side of head

Touch Cues Inventory Example: Focus on Hospital Experiences

Create an *inventory* of touch cues for a child, which can be consistently used by everyone who interacts with that child. Choose events or actions/interactions that happen underlined frequently and the child may have difficulty anticipating otherwise. Start with between 5-10 touch cues.

For example

Action/Event	Touch Cue	Comments
Hello/greeting	Light touch on shoulder	Allow 5 seconds wait time, pair with verbal greeting
Changing/toileting	Light touch on hip/side	Allow 5 seconds wait time, pair with "Time to change your diaper"
IV-related action	Light touch on forearm	Allow 5 seconds wait time, pair with "I'm going to change/etc. your IV now…"
Taking hands to show an object/sensory toy	Light touch on back of hand	Allow 5 seconds wait time, pair with "I'm going to take your hand to show you something…"
Using massager/sensory item	Light touch on place on body where you will place the sensory item before direct contact with the item itself	Allow 5 seconds wait time, pair with language briefly stating what will happen

Name Cues

- A concrete representation of an individual
- A feature of or something a person always wears or has with them
- Used to start and end interactions
- Helps students anticipate and set expectations
- Teaches self concept and concept of others
- Necklace, ring, glasses, hair, etc…
- Different from a name sign

Active Learning - Little Room

How can we make active learning environments in the home and classroom/EI and therapy spaces?

http://www.youtube.com/wa

Implications of Positioning

Positioning and Adaptations for Students with Deaf-Blindness and/or Multiple Disabilities
Chart for Planning Activities

Activity	Position of Student (Seated, standing, moving/walking, side-lying, supine, prone, kneeling, cross-legged, etc.)	Physical adaptive equipment needed (stander, assistive mobility device, adapted chair or attachment, pillow, tumble form, arm rest, cane, wheelchair, etc.)	Extra adaptations and equipment needed for student to attend (slant board, presentation of materials, visual adapt., etc.)	Physical assistance provided by teacher (Hand under hand, coactive movement, coactive manipulation, physical support, etc.)

"Self-Stim in the Pursuit of Leisure"

- We all have self-stimulation behaviors
  - What are yours??

- Self-stimulation = seeking balance & comfort
  - Fulfill multisensory functions and preferences

- What is the purpose of self-stim for your child/student?

(Adapted from Moss & Blaha. 1993)

Sensory Channels and "Behaviors"

Channel	" Creative Variations Which May Plug You Into a Written Behavior Plan"
Tactile	Pulling hair, lying in front of the air vent, slapping face/ear, playing with spit, rubbing head
Proprioceptive	Burrowing into furniture, wrapping arms inside tee-shirts, wrist flapping
Visual	Flicking hand in front of eyes, flipping pages of books, light gazing, playing with transparent or shiny objects, eye poking
Auditory	Vocalizing or making sounds, banging on objects, tapping objects together next to ear
Olfactory	Rubbing feces on the body and smelling, smelling other peoples' hands or shoes
Gustatory	Mouthing objects, chewing on hair, sucking on fingers, licking objects
Vestibular	Rocking body, spinning, twirling in swings, head rocking

(Adapted from Moss & Blaha. 1993)

Sensory Channels and "Behaviors"

Channel	" Miss Manners' Guide to Appropriate Self-Stimulation "
Tactile	Twirling hair, drumming fingers, playing with condensation on a drinking glass, fingering fabrics, rubbing eyes
Proprioceptive	Snuggling in quilts, cracking knuckles, jiggling/crossing legs, sitting on your leg
Visual	Gazing at your fingernails, hands and rings, watching television without the sound, window shopping, flipping through magazines
Auditory	Humming/whistling, tapping a pencil on a surface, playing background music
Olfactory	Wearing perfume, sniffing magic markers, scratch and sniff stickers, burning incense
Gustatory	Chewing flavored toothpicks, sucking on mints/hard candy, smoking, chewing on hair, sucking on pens/jewelry
Vestibular	Rocking in chairs or rocking body, amusement park rides, dancing, twisting on bar stools, skating, sliding

(Adapted from Moss & Blaha. 1993)

When is a behavior preventing availability for learning?

When is a behavior supporting availability for learning? ("Sensory Break")

Multisensory overstimulation is observable… if you're paying attention.

What causes "behaviors"?

- Seeking balance
- Response to stress – internal and external
  - Lack of control
  - Lack of other adaptive "coping" mechanisms
  - Barriers to communication

Stress and Behavior

- Study by Nelson, Greenfield, Hyte & Shaffer (2013)

- Measuring cortisol levels before and after intervention

  - Assumptions
  - Results
    Cortisol levels
    Interventions

Maladaptive behaviors may actually serve as a coping mechanism against stress (rather than being an indicator of high levels of stress)

Stress: The Good Cop

Stress is a protective response

- Respond to challenges and take on tasks
- Avoid harm and protect from threat
- Learn what to avoid
- Learn how to remain calm but alert (self-regulation)
- Effective problem-solving, memory bank of strategies
- Norepinephrine promotes brain development
- Encourage a level of risk-taking to learn

(Brown, 2011)

Stress: The Bad Cop

Stress is only helpful if limited

- Stress hormones cause damage if active too long
- Cortisol can damage brain cells, weaken memory
- Excessive constant levels of cortisol can cause further imbalance in the brain's production of stress hormones

TOXIC STRESS – Can cause brain damage, diabetes, blood pressure & heart problems, mental and emotional health issues

(Brown, 2011)

What does TOXIC STRESS look like?

- The stereotype is that stress looks like hyperactivity and nervousness, over-arousal
  - Tantrums, aggressive behaviors

- Stress can also be extreme under-responsiveness and inactivity
  - Exhaustion, shut-down, refusal, learned helplessness
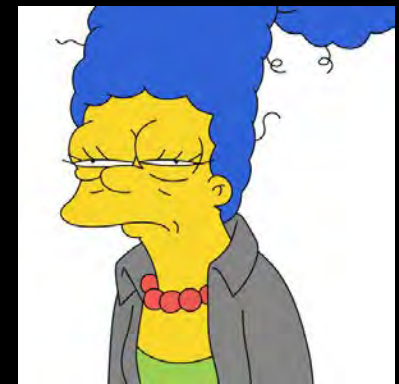
(Brown, 2011)

Protective factors against toxic stress:

- The presence of sensitive/responsive caregivers

- Secure and safe relationships

- High-quality early care and education

- Peer acceptance

- Responsive environments

- Feelings of competence

(Brown, 2011)

When is the child ready for an activity?

Study (Green et al., 1994):
- 98% trainers (teachers): Reported it was helpful to conduct training when students were alert vs non-alert
- 69% reported postponing training due to non-alertness

How can we promote alertness
when a child is non-alert?

Calming and Alerting Stimuli

CHANNEL	CALMING	ALERTING
Vestibular	Slow rhythmic rocking	Fast irregular spinning
Tactual	Firm touch, warmth	Light touch coolness
Auditory	Soothing music, quiet rhythm	Fast loud music
Olfactory	Pleasant scents	Strong pungent odors
Visual	Dim light	Bright Light

Different sensory systems = differences in what is alerting & calming

(Sam Morgan, adapted from Guess et al., 1988)

Preferred Sensory Modalities

- Visual
- Auditory
- Vestibular
- Proprioceptive

- Kinesthetic
- Olfactory
- Gustatory

Which are primary/secondary/tertiary for:
- Literacy & other instructional curricula
- Communication & interaction
- Environmental information & feedback

Identifying Sensory Preferences

Adapted Version of Koenig and Holbrook's Sensory Channel Form

(from *Learning Media Assessment of Students with Visual Impairments*,
1995, Texas School for the Blind)

V = visual; T = tactile; A = auditory; M = movement; S = smell

Child's Name: _____   DOB: _____

Completed By:_____   Date Completed: _____

Behavior	**Sensory Avenue(s) Utilized**
Behavior Observation #1	V T A M S
Behavior Observation #2	V T A M S
Behavior Observation #3	V T A M S
Behavior Observation #4	V T A M S

What calms the child? (describe)	V	T	A	M	S
What alerts the child? (describe)	V	T	A	M	S
What stresses the child? (describe)	V	T	A	M	S
What overloads the child? (describe)	V	T	A	M	S
What are the child's favorite toys? (describe)	V	T	A	M	S
What activities does the child anticipate? (describe)	V	T	A	M	S
What motivates the child to move? (describe)	V	T	A	M	S

"LIKES" INFORMATION

Child:	Date:

FOODS taste/ texture	SMELLS	TOUCH texture/ hugs/ fabrics light - heavy	MOVEMENT rock/ bounce swing	VIBRATION car ride toys/ appliances	SIGHTS lights/colors	SOUNDS voices/ music pitch/ loudness environmental

MUSCLES push - pull bear weight	PEOPLE	PLACES	ACTIVITIES	TOYS	SELF STIMULATION BEHAVIORS	OTHER

WSDS Washington Sensory Disabilities Services

http://www.wsdsonline.org/

Rev 9/12

"DISLIKES" INFORMATION

Child:	Date:

FOODS	SMELLS	TOUCH	MOVEMENT	VIBRATION	SIGHTS	SOUNDS
taste/ texture		texture/ hugs/ fabrics light - heavy	rock/ bounce swing	car ride toys/ appliances	lights/colors	voices/ music pitch/ loudness environmental

MUSCLES	PEOPLE	PLACES	ACTIVITIES	TOYS	SELF STIMULATION BEHAVIORS	OTHER
push - pull bear weight						

Page 2 of 2

WSDS Washington Sensory Disabilities Services

http://www.wsdsonline.org/

Rev 9/12

Sensory Choices & Switch Access
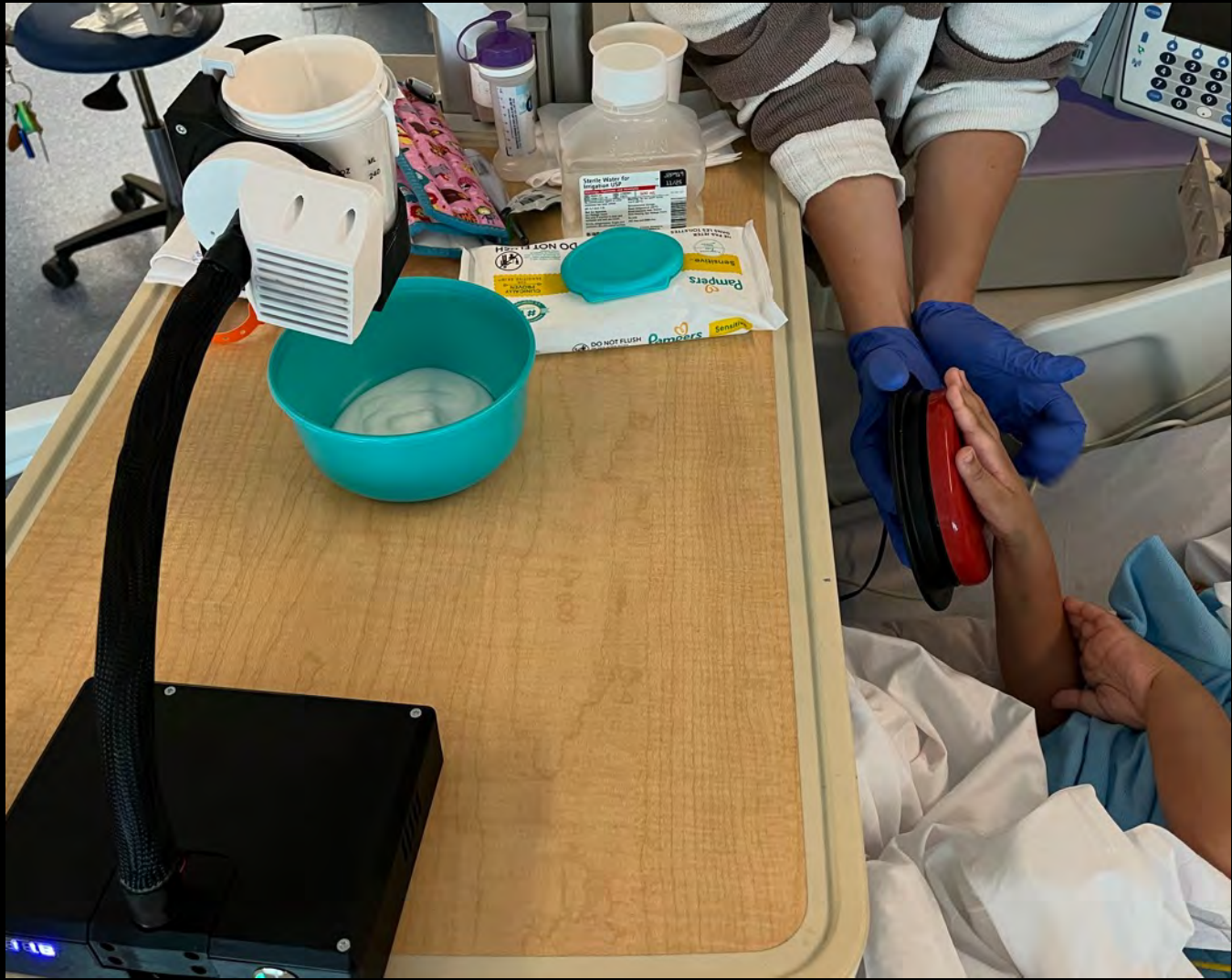
Make tangible symbols (tactile and/or visual) of common sensory preferences/choices

Tangible symbols example: for trach change

Informal Functional Hearing Evaluation (IFHE)

Developed by Texas School for the Blind & Visually Impaired

Outreach Programs

http://www.tsbvi.edu/ | 512-454-8631 |1100 W. 45th St.| Austin, TX

Assessing Communication and Learning in Young Children Who are Deafblind or Who Have Multiple Disabilities

Edited by Charity Rowland, Ph.D.

https://documents.nationaldb.org/DeafBlindAssessmentGuide_Rowland.pdf

Involve the family!

HOME Talk — a Family Assessment of Children who are Deafblind

https://documents.nationaldb.org/HomeTalk.pdf

Biobehavioral States: What are they?

- **States** refer to the condition of a person at a particular moment

- **Biobehavioral** refers to the influences on a child's state

  - Internal Factors
  - External Factors

Internal and External Factors that Influence Availability to Learn

A student's availability to learn changes moment by moment based on the balance between what is happening inside him and what is happening outside him.

External factors:
- Lighting (location and type)
- Background noise
- Smells
- The number of people and their movement around the student
- Tactual input
- Physical supports, positioning, or equipment

Internal factors:
- How the student feels physically & emotionally
- Medical conditions
- Illness or pain
- Impact of medications
- Amount of sleep the night before
- Impact of visual, auditory, and tactile abilities on learning
- Sensory processing or sensory integration difficulties

(Scoggin et al., 2014; OHOA Module 5)

Bio Behavioral States:

Carolina Record of Individual Behavior

- Deep sleep
- Intermediate sleep
- Active sleep
- Drowsy
- Quiet awake
- Active awake
- Fussy awake
- Mildly agitated
- Uncontrollably
Agitated

D. Guess et al 1988, 1993

- Sleep States
  - Inactive
  - Active
- Indeterminate States
  - Drowsy
  - Daze
- Preferred awake state
  - Inactive alert
  - Active alert
- Other awake States
  - Awake active Stereotypic
  - Crying agitated

Assessment of Biobehavioral States

- Purpose: To generate information that supports an intervention plan
  - Increase availability for learning

  - *Modify internal and external factors*
  - The environment and presentation of materials
  - Communication & interactions
  - Schedule and timing
  - Biophysical management plan: meds, food/liquid, sleep, positioning

Assessing Bio Behavioral States:
What are the steps?

Part 1
Gather information about the 24 hours before observation

Part 2
- Observation and assessment of states, environments, and input

Part 3
- Summarize and develop strategies for intervention

Food and Liquid Information
Each time the student eats something, drinks something, or is tube feed, enter the following information on the grid.

type	time start	time stop	amount	comment
yogurt - a	9ᴬ	9²⁰ᴴ	2 oz	resisting, "spitting"
baked chicken rice & carrots - pureed - milk added	11⁴⁵ᴬ	12³⁰ᴾ	almost all - approx. 8 oz of pureed food + liquid	
pears - pureed			approx 2oz milk	
milk c̄ cup	-			Quiet & awake most of the time
				___ opened her mouth slightly when food offered - occ. "spitting or pushing
milk	___ 30ᴾ	1³⁵ᴾ	sips	

Medication Information
Each time the student takes a prescription or over the counter medication

Type	Time	Amount	Comment
Tegretol Suspension	8:20 a.m.	200 mg	
Dimetap Elixir	8:20 a.m.	10 cc	for congestion
Dimetap Elixir	12:30 p.m.	10 cc	
Tegretol Suspension	4:30 p.m.	200 mg	
Dimetap Elixir	4:30 p.m.	10 cc	

Seizure Information
Each time a seizure occurs, enter the following information on the grid.

start time	stop time	description	comment
8⁵⁷ᴬ	8⁵⁷	- 30 seconds -	startle, head to ⊕, ⊖ arm thrashing
12²⁰ᴾ	12²¹	- 75 seconds	shriek, head to ⊕ arms thrashing, crying

Sleep Information

Start Time	Stop Time	Location	Comments
9:00 p.m.	12:00 p.m.	Bedroom	Cried to request in bed change in position
12:15 p.m.	3:20 p.m.	"	"
3:28 p.m.	6:15 p.m..	"	Playing quietly in bed when checked at 6:15

(Smith & Shafer, TSBVI)

State Key: _ = Seizure; S = Sleep; D = Drowsiness; QA = Quiet Awake;
AA = Active Awake; FA = Fussy Awake; MA = Mild Agitation;
UA = Uncontrollable Agitation.

Time	Activity	Ambient Conditions	Social Conditions
8:15	Arrival	Outdoors cold, windy, noisy chairlift in bus	Greeted by TA Linda
8:30	Breakfast	Normal temperature and lighting	0
8:45	Tooth-brushing	Noisy bathroom, very bright lighting	Hand-over-hand manipulation; L
9:00	Hair Drying	Normal temperature and lighting	Talking; Linda
9:15	Hair Brushing	Normal temperature and lighting	Talking; Linda
9:30	Drama Class	Dark stage area, echoes	Surrounded by peers
10:00	Changing	Normal temperature and lighting	Patting, talking; Linda
10:15	Mail Delivery	Many changes; different noise levels	Interaction with 6 different adults

(Smith & Shafer, TSBVI)

Assessment of Biobehavioral States:
Supporting Availability for Learning for Students with Multiple Disabilities
including Deaf-Blindness & Profound Intellectual & Multiple Disabilities

Chris Russell, MS. Ed., TVI

NYDBC
NEW YORK
DEAF BLIND
COLLABORATIVE

CODING KEY

Behavior State Codes:
AI: Asleep-Inactive
AA: Asleep-Active
DR: Drowsy
DA: Daze
AWIA: Awake-Inactive-Alert
AWAA: Awake-Active-Alert
AWASS: Awake-Active-Self-Stimulatory
CR: Crying
Z: Seizures

Environmental Lighting (L):
Dk: Dark
Dm: Dim
BN: Bright natural (sun)
BL: Bright lamp/lightbulb

Position
SE: Seated
ST: Standing
PR: Prone
SP: Supine
SI: Side-lying
RP: Repositioning

Sound Level (SL):
Q: Quiet
LB: Low background noise
HB: High level backgr. noise
N: Noisy, direct

Social:
A: Alone
P: Proximity (within 3')
PC: Physical Contact
HUH: Hand Under Hand
HOH: Hand Over Hand

Temperature (T):
C: Cold
Cl: Cool
W: Warm
H: Hot
VH: Very Hot (humid)

Communication partner
N: No partner
T: Teacher
A: Aide
P: Peer

Coding systems partially adapted from:

Arthur, M. (2004). Patterns amongst behavior states, sociocommunicative, and activity variables in educational programs for students with profound and multiple disabilities. *Journal of Developmental and Physical Disabilities, 16*(2), 125-149.

Guess, D., Mulligan-Ault, M., Roberts, S., Struth, J., Siegel-Causey, E., Thompson, B., ... & Guy, B. (1988). Implications of biobehavioral states for the education and treatment of students with the most profoundly handicapping conditions. *Research and Practice for Persons with Severe Disabilities, 13*(3), 163-174.

Instructions for Completing the Assessment of Biobehavioral States:

1. Review the results of prior assessments, and conduct additional sensory, communication, and preferences assessment needed to gather student-centered information that will help guide biobehavioral assessment and intervention. See *Additional Resources* below.

2. **Background Information:** Collect background information within 24 hours of observation, with support of the family and/or home management team. (See page 3)

3. Pick a time interval for using the Observation forms. If assessing a half day or full day, you may want to use 15-minute or 30-minute intervals. If assessing a single contained activity, you may want to use 1-minute intervals.

4. **Observation Form:** On the observation form, complete data at the exact time interval selected above. Describe the activity briefly, and circle codes for data across all areas: Behavior State, Position, Environmental (ambient: Lighting, Temperature, Sound Level), Social Context, and Communication Partner. You may want to add additional notes on the side bar as needed.

5. Duplicate as many copies of the observation forms needed to complete data for the allotted time of the observation (whether a single activity, half day or full day).

6. **Informal Evaluation:** Note informal trends observed for each behavior state. Is there a time of day at which the student tends to be in a certain state? Are certain positions, environmental contexts, social contexts, or specific communication partner interactions associated with a specific behavior state?

7. **Recommendations:** Refer to the Recommendations form as a guide to provide the collaborative team (including the family) with clear recommendations for next steps in modifying the biophysical, environmental, and/or communication plan in order to increase the student's availability for learning.

Additional Resources Supporting Assessment and Intervention:

The Communication Matrix (assessment of expressive communication appropriate for learners with multiple disabilities)

Assessment of Learning & Communication in Children who are Deafblind or Who Have Multiple Disabilities (assessment guide)

HomeTalk: A Family Assessment of Children Who are Deafblind

WSDS Likes/Dislikes Form (informal sensory preferences assessment)

Sensory Channel Form (adapted by T. Anthony)

"Talking the Language of the Hands to the Hands" (Miles, 2003; Rev. Miles, Nelson & Pellerin, 2015)

Open Hands Open Access DeafBlind Intervener Modules (free online training modules for interveners and collaborative team members)

Food/Liquid Intake

Type of food/liquid	Time Start	Time Stop	Amount (ounces)	Comments

Medication information

Type	Time	Amount (cc / mg)	Comments Description of side effects

Sleep Information

Start Time	Stop Time	Location	Comments

Elimination activity

Time	Urine (U) or BM	Comments

Seizure Activity

Start Time	Stop Time	Description	Comments (aura, state before and after seizure)

Additional Comments:

Adapted from Smith, M., & Shafer, S. Assessment of biobehavioral states and analysis of related influences. See/Hear Newsletter. www.tsbvi.edu

Student: _____ Date: _____ Data Collectors: _____

Time	Activity	Behavior State	Position	Environmental (Ambient)	Social Context	Communication Partner
		AI AA DR DA AWAI AWAA CR Z	SE ST PR SP SI RP	L: Dk Dm BN BL T: C Cl W H VH SL: Q LB HB N	A P PC HUH HOH	N T A P
		AI AA DR DA AWAI AWAA CR Z	SE ST PR SP SI RP	L: Dk Dm BN BL T: C Cl W H VH SL: Q LB HB N	A P PC HUH HOH	N T A P
		AI AA DR DA AWAI AWAA CR Z	SE ST PR SP SI RP	L: Dk Dm BN BL T: C Cl W H VH SL: Q LB HB N	A P PC HUH HOH	N T A P
		AI AA DR DA AWAI AWAA CR Z	SE ST PR SP SI RP	L: Dk Dm BN BL T: C Cl W H VH SL: Q LB HB N	A P PC HUH HOH	N T A P
		AI AA DR DA AWAI AWAA CR Z	SE ST PR SP SI RP	L: Dk Dm BN BL T: C Cl W H VH SL: Q LB HB N	A P PC HUH HOH	N T A P
		AI AA DR DA AWAI AWAA CR Z	SE ST PR SP SI RP	L: Dk Dm BN BL T: C Cl W H VH SL: Q LB HB N	A P PC HUH HOH	N T A P
		AI AA DR DA AWAI AWAA CR Z	SE ST PR SP SI RP	L: Dk Dm BN BL T: C Cl W H VH SL: Q LB HB N	A P PC HUH HOH	N T A P
		AI AA DR DA AWAI AWAA CR Z	SE ST PR SP SI RP	L: Dk Dm BN BL T: C Cl W H VH SL: Q LB HB N	A P PC HUH HOH	N T A P

Comments: (Include specific *time*):

Informal Evaluation:

Note any informal trends observed in each behavior state, in relation to: Time, Position, Environmental, Social Context, Communication Partner. For example, AA: Trend Position = Supine (Student was observed generally in Asleep-Active position when supine).
*Do not note trends unless observed specifically.

Behavior State	Time	Position	Environmental (Ambient)	Social Context	Communication Partner
AI					
AA					
DR					
DA					
AWAI					
AWAA					
CR					
Z					

New York Deaf-Blind Collaborative, 2016

Recommendations for Intervention

Biophysical Management Plan

Social Contexts

Student's Schedule

Communication Partners

Positioning

Communication & Interaction Supports

Environmental Modifications

Materials & Instructional Routines

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Questions?

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