INTRODUCTION TO LEARNERS WHO HAVE DEAF-BLINDNESS

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FOR THE MONTANA DEAF-BLIND PROJECT

AGENDA

- Functional definition of deaf-blindness
- Primary etiologies of deaf-blindness
- Four over-arching categories of deaf-blindness
  - Time of onset of loss(es)
  - Degree of loss(es)
  - Type of loss(es)
- General impact of deaf-blindness on environmental interactions

ACTION PLAN

Please record your thoughts, regarding how you *might* incorporate information from today's webinar in your family life / daily practice.

Thank you!

WHAT IS DEAF-BLINDNESS?

DEAF-BLINDNESS does NOT imply that an individual sees or hears absolutely nothing

DEAF-BLINDNESS simply means that the individual experiences *both* a vision and a hearing loss, of some type, to some degree.

DEAF-BLINDNESS STATISTICS

In the United States, 9,904 children and youth (birth through 21 years) experience deaf-blindness (NCDB, 2018)

- Of this number, approximately 5% experience total deafness and total blindness
- But approximately 91% of these children and youth also experience at least one additional disability (but not necessarily cognitive disability)

HOW DO YOU KNOW IF SOMEONE HAS DEAF-BLINDNESS?

Two key questions to ask, when assessing whether a learner has DB:

- Does she have enough vision to compensate for her lack of hearing?

- Does she have enough hearing to compensate for her lack of vision?

(John McInnes)

WHAT SENSES DOES DEAF-BLINDNESS AFFECT?

Deaf-blindness…

- affects two of a learner's three **DISTANCE** SENSES and
- necessitates that she use **IMPACT** SENSES (i.e., taste, tactile, kinesthetic) to gather information

DISTANCE SENSE - #1

Distance senses: **SMELL**

- Can be used to identify a person
- Can evoke strong memories
- **Is smell even available???**

DISTANCE SENSE - #2

Distance senses: **HEARING**

- Important for understanding spoken (i.e., oral) language
- ALSO…provides environmental cues
- **Is hearing available in one ear or both?**

DISTANCE SENSE - #3

Distance senses: **VISION**

- Provides info re: what is in the environment
- Lets a person know if things, or people, are moving toward / away from her, or standing still
- Tells a person is others are trying to communicate with her through manual sign or gestures
- Is vision available centrally? Periphally? Are there blind spots? How far away can she see clearly? etc., etc….

CATEGORIZING the DISABILITIES of LEARNERS WHO HAVE DEAF-BLINDNESS

ETIOLOGIES of DB

In general, children might be at risk for experiencing deaf-blindness, due to a:

- hereditary syndrome or disorder
- pre-natal condition
- post-natal condition
- family history
- head injury or direct trauma to ear / eye
- prematurity

ETIOLOGIES of DB

In the 2018 NCDB annual census report:

- More than 70 specific etiologies are listed as identified causes of deaf-blindness (birth through 21 years)
- Twelve unique etiologies are identified as the cause of at least 100 cases of deaf-blindness
- Other etiologies are extremely rare, with fewer than five cases reported nationally across the US (e.g., Batten disease, Prader-Willi syndrome)
- Approximately 19% of children and youth with deaf-blindness have no determined etiology (n = 1745)

CATEGORIES OF DB

1. by **time(s) of onset** of sensory loss
2. by **degrees / types** of sensory loss
3. **BOTH**—by time(s) of onset *and* degrees of both vision and hearing

By far, the best predictor of an individual learner's needs / skills is the <u>third</u> model.

CATEGORY #1 – TIME OF ONSET

#1 - By TIME OF ONSET of sensory loss

- congenital – present at birth or *very shortly* thereafter
- adventitious – some extended time after birth, due to illness or injury

Time of onset of loss needs to be considered in regard to *both* vision and hearing.

TIME OF ONSET

TIME OF ONSET of sensory loss is important because a child, who has experienced…

- Hearing – *might* have some recollection of sound / sound properties
- Vision – *might* have some residual visual imaging (of boundaries, people)

TIME OF ONSET

Neuroscience has clearly demonstrated the benefit of early sensory input

- Sensory input begins structural changes in the brain, from the time of birth
- Experiencing hearing and / or vision is sufficient to initiate auditory and visual cortical development
- Early sensory input is critical to future sensory development (i.e., the timing of a premature infant's birth affects potential for developing sensory problems)
- The brain is incredibly facile at re-purposing "unused" neurons

TIME OF ONSET

KEY is the point at which the developing sensory input makes the transition to higher order (i.e., cognitive) processes

- At what point is the sensory input sufficient to establish connections in the system?
- Connections in the system lead to development that yields meaningful, lasting sensory experiences (i.e., functional, beneficial skills that learners can utilize)

TIME OF ONSET

KEY, also, is the individualized development of visual and / or auditory skills

- Literature highlights *"pre-lingual"* or *"post-lingual"* deafness as key marker, even approximating 2 – 3 years of age
- Propose much younger age, perhaps as young as 18 months, due to development of:
  - Visual searching, due to awareness of the world outside oneself
  - Ability to "be vertical"—due to spatial awareness
  - Relationship info gained through dyadic interaction (i.e., bonding, facial expressions, etc.)

CATEGORY #2 – DEGREE/TYPES

#2 - By DEGREES/TYPES of sensory loss

- partial - some functional skills remain
- total - essentially no functionality can be gained through that sensory channel
- unilateral vs. bilateral loss

Degree of sensory loss needs to be considered in regard to *both* vision and hearing.

CATEGORY #3 – TIME OF ONSET AND DEGREES/TYPES

#3 - By TIME(S) OF ONSET <u>and</u> DEGREES / TYPES of sensory loss

- Congenital hearing *and* vision losses
- Adventitious hearing *and* vision losses
- Congenital hearing loss and adventitious vision loss
- Congenital vision loss and adventitious hearing loss

CATEGORIZING DB

Even in this dual model,
the degrees / types of an
individual learner's
hearing and vision losses
must be considered individually!

Remember:

Learners who have deaf-blindness are an incredibly heterogeneous group!

Congenital Hearing *and* Vision Losses

- Rubella (n=33 in 2018)
- Cytomegalovirus (CMV) (significant problems, 1 in 5)
- Cephalies
- Syphilis
- Toxoplasmosis
- Toxins (environmental, ingested)
- Birth Trauma

Congenital Hearing *and* Vision Losses (cont.)

- Prematurity – most common cause, *overall* (n=991)
  (Retinopathy of Prematurity—ROP)
- Cerebral palsy
- Leber syndrome
- CHARGE syndrome – most common hereditary syndrome (n=958)
- Trisomy 13 (Patau syndrome)

Adventitious Hearing *and* Vision Losses

- Trauma
- Meningitis
- Encephalitis
- Toxins (environmental, ingested)
- Usher Syndrome, Type III (develop during late childhood or early teen / adolescent years)
- Friedrich's Ataxia
- Neurofibromatosis

Congenital Hearing Loss – Adventitious Vision Loss

- Shaken Baby Syndrome
- Diabetic Retinopathy
- Usher Syndrome, Types I (typically a field loss is identified during early elementary years) and

  Type II (typically noted during middle to late teen years)
- Macular Degeneration (usually older)

Congenital Vision Loss - Adventitious Hearing Loss

- Trauma
- Injury / Tumor
- Meningitis
- Encephalitis

IMPACT of DEAF-BLINDNESS ON ENVIRONMENTAL & ACADEMIC INTERACTIONS

DEAF-BLINDNESS IS A DISABILITY …

- about INFORMATION GATHERING
- which LIMITS ACCESS
- which is EXPONENTIALLY MORE than a hearing loss plus a vision loss

INFORMATION GATHERING

Types of “Information Gathering” (i.e., LEARNING)

- Direct learning
- Secondary learning
- Incidental learning

PARTNERING OR TEACHING A LEARNER WITH DEAF-BLINDNESS

- Partnering with a learner with deaf-blindness involves…

- **INVITING THE CHILD (ADOLESCENT) "OUT,"** to join you in the world, and to build levels of connections with her

PARTNERING OR TEACHING A LEARNER WITH DEAF-BLINDNESS

Deaf-blindness requires a learner's partners to take time to…

- plan how a learner will **RECEIVE** information in every activity
- plan what a learner will **DO** in every activity, to communicate **UNDERSTANDING**
- consider the IMMEDIATE physical, visual, and auditory ENVIRONMENTAL CONTEXTS of every activity in the assessment

PARTNERING OR TEACHING A LEARNER WITH DEAF-BLINDNESS

For the majority of individuals who experience deaf-blindness, their RECEPTIVE and EXPRESSIVE modes of communication are likely to be different.