Deaf-Blindness 101: Communication and Equal Access

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-in collaboration with-

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Today we’ll cover…

- What deaf-blindness encompasses
- Communication barriers
- Incidental learning
- Sensory channels and strategies
- Communication methods and support services
- Self-determination
- Accommodations and strategies
- Schedules
- Etiquette
Who is Deaf-Blind?

- Dual-sensory loss
  - Some combined hearing and vision loss
- Most aren’t profoundly deaf and totally blind
- Both hearing and vision loss are on a continuum
- Underreported population
- May have one loss and develop the other

(Koehler & Locke, 2018)
Deaf-Blind Impact

• Impact depends on several factors
  – Degree of each loss
  – Stability of each loss
  – Age of onset
  – Additional disabilities
  – Quality of educational services
  – Language exposure and development
  – Movement and motor development
  – Cognitive development
  – Emotional and social development

(Koehler & Locke, 2018)
(Minnesota Department of Human Services, 2012)
Hearing Loss

• Hard of Hearing
  – Mild to Moderate
• Deaf
  – Severe to Profound
• Hearing Loss
  – Ear
  – Auditory
Vision Loss

- Light Perception vs. No Light Perception
- Field Loss
- Visual Impairment: Visual Acuity- 20/70 or worse
- Legally Blind: Visual Acuity- 20/200 or worse

Vision Loss
- Ocular
- Cortical

(Helen Keller National Center, 2019)
(Minnesota Department of Human Services, 2012)
Different Visual Conditions

- Normal Vision
- Diabetic Retinopathy
- Cataracts
- Age-Related Macular Degeneration
- Glaucoma

(Eyedocs, n.d.)
Common Syndromes Associated with Deaf-Blindness

• **Age-related hearing and vision loss**
  – Cataracts
  – Glaucoma
  – Age-related macular degeneration
  – Diabetic retinopathy

• **Usher Syndrome**
  – Hearing loss and retinitis pigmentosa (progressive visual condition)

• **Congenital Rubella Syndrome**

• **CHARGE Syndrome**

• **Prematurity**

• **Norrie Disease**
  – Rare X-linked genetic disorder

(Helen Keller National Center, 2019)
(Minnesota Department of Human Services, 2012)
Communication Barriers

- Lack of access to information
- Lack of control (dependent on others)
- Lack of mobility
- Lack of socialization
- Confidence
- Frustration
- Extreme isolation
- Depression

70% of information is received visually

(Minnesota Department of Human Services, 2012)
Impact on Incidental Learning

Typical Sensory Access

Direct Instruction
Hands-on experiences

Secondary Learning
Listening to presented information

Incidental Learning
Occurs automatically without much effort

Congenitally Deaf-Blind

(Intervener, n.d.)
Sensory Channels

- Can access language through other means
  - Taste
  - Touch
  - Smell
  - Proprioception (body position and movement)

- Passive touch experiences (receptive)
  - Happen to us
  - Surfaces we come in contact with

- Active touch experiences (expressive)
  - Choose to explore
  - Add to our knowledge of the world

(Texas School for the Blind and Visually Impaired, n.d.)
Mutual Tactile Attention

• Tactile equivalent of pointing
• Gives meaning to what is happening with the individual
• Importance:
  – Joint attention
  – Sharing an experience
  – Exploring with more confidence
  – Shows an interest in what the individual is doing in a way that makes sense to them
  – Provides a foundation for conversational turn-taking
• Allows them to move at their own pace
• Follows the lead of the individual
• Slide your hand next to the individual’s hand while they are exploring an item or working on an activity and become engaged in what they are doing

(Alsop & SKI-HI Institute, 2002)
(Project SALUTE, n.d.)
Sam is not deaf-blind but watch his interactions with Hayley

Patricia is deaf-blind and has some residual hearing remaining

(Sound is not necessary for this video)

(Hewett, 2017)
(Scoggin, et. al., 2016)
Communication Methods

- American Sign Language
- Tactile Sign Language
- Braille
- Print-On-Palm
- Touch Signals
- Communication Cards for Mobility
- Speaking
- Communication Access Real-time Translation (CART)
- Augmentative and Alternative Communication
- Technology

(Helen Keller National Center, 2019)
Direct Support Services

- **Interveners**
  - Specially trained to provide 1:1 support in school settings

- **Support Service Providers (SSPs)**
  - Specially training individuals who support individuals with deaf-blindness to access their environment and make informed decisions
  - Consumer must be self-directed

- **Interpreters**
  - Facilitate communication between people
  - Tactile sign to spoken language or spoken language to tactile sign
  - Incorporate visual and environmental information
  - Understand modifications for vision loss

- **Orientation and Mobility Specialists**
  - Helps a person with deaf-blindness to move independently and navigate new environments

(Alsop, et al., 2007)
Self-Determination

- Learned helplessness

- Self-Determination (basic to more complex)
  - Choice-making
  - Decision-making
  - Problem-solving
  - Goal-setting and attainment skills
  - Independent living skills (risk-taking and safety skills)
  - Self-observation, evaluation, and reinforcement skills
  - Self-instruction skills
  - Self-advocacy and leadership skills

(Maier, 2013)
Accommodations

Accommodations should always be based on how much hearing and vision the individual can access

Visual Accommodations

- Well lit areas
- Contrasting backgrounds
- Reduced visual distractions
- Individual’s back to light source/windows (reduce glares)
- Items presented within field of vision
- Large print
- Adapted daily living equipment
- Additional time

Auditory Accommodations

- Reduced background noise
- Close face-to-face communication (visible face and mouth)
- Gestural and/or visual/tactile supports
- Preferred seating
- Address individual by name before speaking to them
- Additional time

(Minnesota Department of Human Services, 2012)
Routine and Daily Schedules

- Used to prepare individual for transition
- Start with preferred activity
- Something they actually experience
  - What it feels like to the individual
- Contrasting background
- Can include English, Braille, and/or pictures
Other Strategies

- Strategies
  - Use the individual’s preferences (likes/dislikes)
  - Use the individual’s strongest sensory channel
  - Active participation
  - Anticipation
  - Implement wait time for the individual to process
  - Amount and pace of input
  - Imitating the individual
  - Mutual tactile attention
  - Hand-under-hand
  - Following the individual’s lead
  - Best communication partner
  - Maximize visual and auditory access (maximize with contrast)
Basic Etiquette

• Tips for interacting with an individual who is deaf-blind
  – Treat the person the same way you would treat anyone else
  – Get the person's attention by gently touching them on the arm or shoulder, then wait to be acknowledged
  – Ask the person how they prefer to communicate, where you should sit, etc.
  – Don't assume that the person knows who you are. Identify yourself every time you enter or leave a room, join a conversation, etc.
  – Don't leave the room without telling the person
  – Communicate directly with the person who is deaf-blind, even when communicating through an interpreter, family member or other support person
  – Speak one at a time
  – Don't move objects, such as a glass of water or chair, without telling them that you have done so

(Minnesota Department of Human Services, 2012)
Deaf-blind people can do anything. The question is not whether or not we can or should do something, but HOW we are going to do it. Being deaf-blind, in and of itself, is never the problem; the problem always lies elsewhere, in lack of access, in bigotry and ignorance, in narrow rules and definitions that discriminate against and exclude us. Deaf-blind people are capable of gaining knowledge, thinking critically, and synthesizing and applying information and thought.

- John Lee Clark

(Minnesota Department of Human Services, 2012)
Citations:


• Intervener. (n.d.). Deafblindness. Retrieved from Intervener.org/deafblindness/


Citations:

Thank you!

Questions?

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