

DeafBlind: A Disability of Access

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Statewide Professional Development to Support the Workforce and Low Incidence Disability Areas.

Goals for Today's Session

- Describe the impact of combined hearing and vision loss on learning, communication, people, and the environment.
- Explain why combined hearing and vision loss (DeafBlind) should be considered primary for those who also have multiple disabilities.
- Identify resources for assessment materials and impact statements for evaluation summaries.

Who Is DeafBlind?







How Would Being DeafBlind Affect Your Life?

"It's not about what you cannot do, it is all about what you can do, if given the right supports and environment."

Dr. Jerry Petroff, 2012

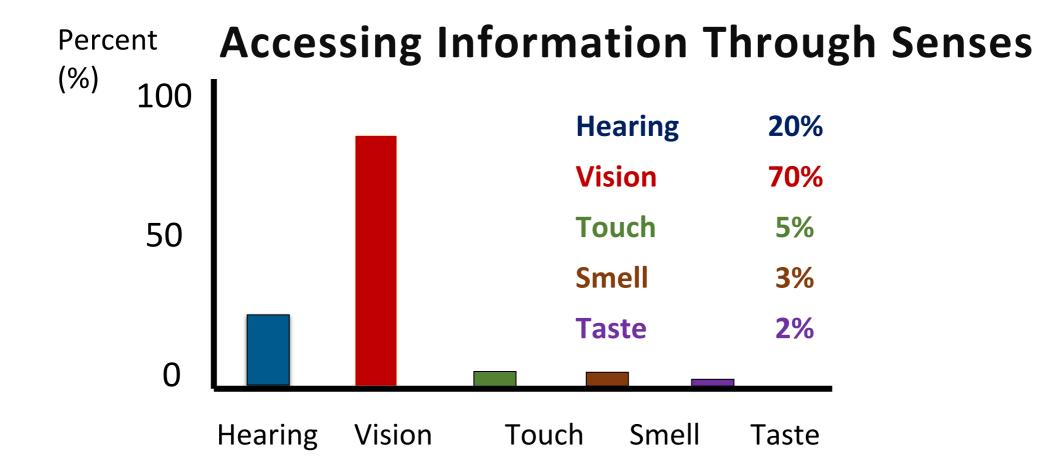
Link to video 2:18: NCDB (YouTube.com)



How Do You Access and Learn Information?

- How do you experience the world?
- How do you learn?
- How do you gain knowledge?

Credit: Dr. Jerry Petroff, 2012



Critical Understanding #1

Approximately 80-90% of sensory information is compromised or missing for children who have combined hearing and vision loss.

Credit: Dr. Jerry Petroff, 2012

Students with deafblindness often experience additional disabilities. More than 80% of deafblind students in Minnesota have additional disabilities.

However, it is deafblindness that must always be considered as their primary challenge to access for communication and learning.

Definition and Examples of Deafblindness

<u>Deafblindness</u> is when a person experiences loss in both hearing and vision. The levels at which hearing, and vision are affected vary greatly.

Only 1% of children identified as deafblind are completely deaf and completely blind. The other 99% have different levels of combined hearing and vision loss. Even when children have the same syndrome, they may be impacted differently. Each person is unique.

Critical Understanding # 2



Deafblindness does **not** equal deaf plus blind.

Some Etiologies of Deafblindness

Etiologies of Deafblindness

- 1. Complications of Prematurity
- 2. Congenital Prenatal Causes
 - Congenital Cytomegalovirus (cCMV)
 - Hydrocephaly
 - Microcephaly
 - Fetal alcohol syndrome
 - Maternal drug abuse
 - Congenital Rubella

3. Hereditary/Chromosomal Syndromes

- CHARGE
- Usher
- Down
- Stickler

4. Postnatal Causes

- Asphyxia
- Head injury/trauma
- Meningitis

Congenital Deafblindness

Deafblindness can occur at birth or soon after. This is called congenital deafblindness.

Children with this type of deafblindness may struggle to with concept development, language, and many other areas.

Credit: National Center on Deafblindness OHOA Intervener Learning Modules



Acquired Deafblindness

Combined hearing and vision loss can also occur later in life. This is called acquired deafblindness (i.e., when a student's hearing or vision levels change.)

Note: Tracking hearing and vision levels is important, especially for children and youth with certain etiologies.

Credit: National Center on Deafblindness OHOA Intervener Learning Modules



Unduplicated Child Count: Primary Disability on IEP

The Minnesota Department of Education tallies their child count numbers in special education by the primary disability on the IEP.

2022-2023: DeafBlind – 119 students

2022-2023: Severely Multiply Impaired – 1,626 students





Minnesota DeafBlind Child Count = 363 2022-2023



Additional Disability	Total Numbers	Percentage of Minnesota Students with Combined Hearing and Vision Loss
Developmental Cognitive Delay	245 out of 363	67%
Physical Impairments	247 out of 363	68%
Complex Health Care Needs	226 out of 363	62%
Cortical Visual Impairment (CVI)	110 out of 363	30%

DeafBlind as the Primary Disability

Students with combined hearing and vision loss (deafblindness) often may present with additional disabilities.

However, it is strongly encouraged that deafblindness be considered as the primary disability because deafblindness impacts **access** to **people, the environment, communication, language, and learning**.

** At least 80-90% of sensory information is compromised or missing. **

Simulations

Disclaimer: There is debate about the value of short simulation activities for participant understanding. Note that these short clips are not the experience of every person with combined hearing and vision loss.

Goal of this activity: To encourage reflection and consideration of the impact of combined hearing and vision loss on infant, child and youth access to learning.

What is it Like to have Cortical Visual Impairment?

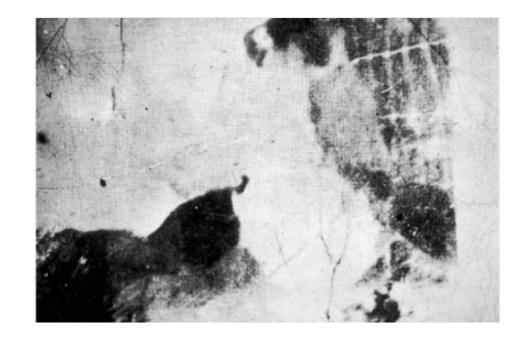
Link to YouTube video 1:05: The New Face of Blindness



What Do Children with CVI See?

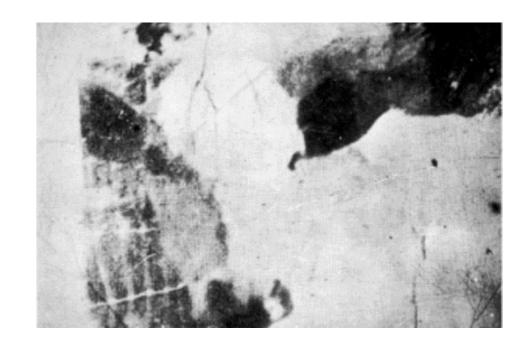
CVI simulation

Figure 1: Children with Cortical Visual Impairment (CVI) have delays in recognition of what the image represents.



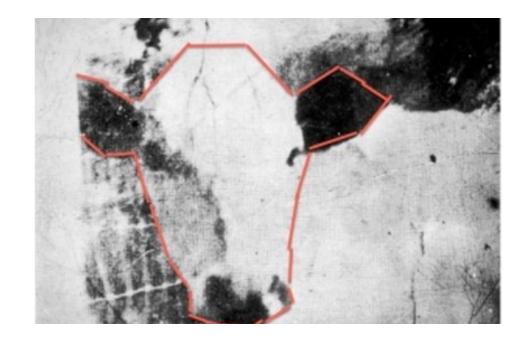
What Do Children with CVI See?

Figure 2: Children with Cortical Visual Impairment (CVI) still searching for the recognition of what the image represents.



What Do Children CVI See?

Figure 3: Children with Cortical Visual Impairment (CVI) can recognize better images representation if the outline of pictures is highlighted.



Spelling Test: Directions:

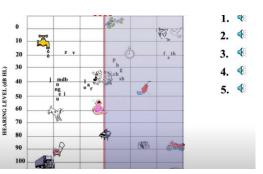
- 1. Write down the five words that you hear.
- 2. Review for accuracy.

Link to YouTube videos:

School Sound Effects (Ambience World)

Unfair Spelling Test 5 words





Simulations for Combined Hearing and Vision Loss Produced by SKI-HI Institute

Link to YouTube videos:

<u>Scattered Blind Spots and Severe Hearing Loss (1:03)</u>

20/200 Visual Acuity and Sloping Hearing Loss (1:04)

Cataracts and Mild High Frequency Hearing Loss (0:59)

Cochlear Implant Simulations Auditory Implant Service



Active Learning and Access for DeafBlind Children

When a DeafBlind child has access, his energy levels, motivation, interactions, and engagement increase.

Link to video 0:09:

<u>Before Active Learning</u>

Link to video 0:31: In Active Learning





Critical Understanding #3: Access of the Hula Hoop



Journal of Visual Impairment & Blindness: An Examination of Interstate Differences in Eligibility Criteria for Deafblindness, June 6, 2023

Journal of Visual Impairment & Blindness

...miscategorizing a student with deafblindness prevents the Individualized Education Program (IEP) team from conceptualizing the immediate and long-term needs of the individual with specific consideration given to the student's level of functional vision and functional hearing. The student's combined hearing and vision must always be a primary consideration; it may not be the focus without the label of deafblind.



What About Severely Multiply Impaired (SMI) as the Primary Disability for Students with Combined Hearing and Vision Loss and Additional Disabilities?

Current MN SMI Criteria Checklist:

MN Department of Education SMI Checklist Link

IDEA's Multiple Disabilities Criteria excludes Deafblindness and recognizes it as a separate disability category.

Most importantly, recognize ACCESS.

The primary disability highlights the access needs. It does not mean the child does not have co-occurring disabilities and does not need other special education services. The need for access is highlighted.

Resources for Assessing Students with Combined Hearing and Vision Loss (Deafblindness) with Multiple Disabilities

Google Site: DeafBlind Resources for

Educators – Assessments

Google Site: DeafBlind Resources for Educators – Writing Impact Statements for Combined Hearing and Vision Loss in the IEP



Interveners

Individuals with **specialized training** to work with children and youth who have combined hearing and vision loss (deafblindness) and work in a <u>one-on-one</u> relationship with children/youth who are deafblind.

<u>Intervener Information on the MN</u>
<u>DeafBlind Project Website</u>



Comparison of Interveners and Paraprofessionals

<u>Link: Comparison of Interveners and Paraprofessionals Document</u>

Find more information about interveners on the Minnesota DeafBlind Project website under the Interveners tab.

Intervener	Paraprofessional	
 Works under the direction of the classroom teacher (regardless of supervisory funding source) 	♦ Works under the direction of the classroom teacher	
◆ Abides by district or agency policies	◆ Abides by district or agency policies	
◆ Assigned to work one-to-one with a student who is deafblind to facilitate the process of intervention	 Usually works with groups of students but can work one-to-one when assigned by the teacher 	
◆ Must have comprehensive specialized training in deafblindness	◆ Typically does not receive disability specific training	
 Has skills in deafblind intervention including communication methods, environmental access, sensory loss, deafblind instructional strategies, and how to create independence rather than dependence 	 Has varying levels of skills dependent on assignment, experience, and training 	
 Prepares materials for the one student who is deafblind with whom he/she works in coordination with the teacher 	 Responsible for materials preparation for entire class as assigned by the teacher (e.g., copying, cutting, activity preparation) 	
♦ Not assigned to do classroom maintenance because of the continuous one-to-one time required by the student with deafblindness	◆ Responsible for classroom maintenance as assigned by the teacher (e.g., bulletin boards, setting up and cleaning up materials)	
◆ Usually attends regularly scheduled planning and feedback meetings with the teacher and other team members	◆ Typically does not attend planning meetings	
 Participates as an active member of the student's team including attendance at IEP meetings in order to contribute valuable day-to- day knowledge of the student 	◆ Generally does not attend IEP meetings	
♦ Not generally assigned to additional school duties because of one- to-one time required by the student	 May be assigned to additional school duties such as lunchroom, bus, playground, etc. 	
◆ Facilitates the student's connection to others by explaining and modeling the student's specific communication system, acting as a bridge to the world, and creating a safe and supportive environment that encourages successful interactions	 Typically is not required to facilitate communication connections between students and others 	

Clarification of Roles of Contracted Nurses, District Health Staff, and Interveners in Educational Settings

<u>Link: Clarification of Roles of</u>
<u>Contracted Nurses, District Health Staff,</u>
and Interveners in Educational Settings

Find more information about interveners on the Minnesota DeafBlind Project website under the Resources for Interveners tab.







Clarification of Roles of Contracted Nurses, District Health Staff, and Interveners in Educational Settings

Roles

Contracted Nursing Services	School District Health Staff	Intervener
Non-district employee. Common licensures include Registered Nurse (RN) or Licensed Practical Nurse (LPN), current licensure by the MN Board of Nursing. Follows all standards of practice according to licensure. Has specialized training and skills to meet the needs of the student(s) with complex health needs. The contract between the district (payer) and the nursing agency (payee) will address the nursing services provided including the student(s) they are assigned to.	Health staff titles may include Registered Nurse (RN), Licensed School Nurse (LSN) or Public Health Nurse (PHN), Licensed Practical Nurse (LPN) or Unlicensed Assistive Personnel (UAP). UAP's are often titled, Health Assistant, Health Associate or Health Paraprofessional. The RN, LSN and/or PHN provide care planning, care coordination, training, and delegation to unlicensed UAP and assignment to LPNs to meet the needs of the student(s) with complex health needs.	Receives specialized training to work with children/youth with combined hearing and vision loss, primarily in a one- on-one relationship. Typically, a non-licensed paraprofessional who is trained in deafblindness.

Supervision and Direction

Contracted Nursing Services	School District Health Staff	Intervener
Health Procedures: The contracted employee is supervised by the agency. Follows all licensed health care provider orders. Collaborates with the district RN/LSN/PHN.	Health Procedures: The district UAP is supervised by the RN/LSN/PHN.	Health Procedures: Intervener may provide limited health services (e.g., tube feedings, medications) as delegated by, trained, and supervised by RN/LSN/PHN. Classroom Activities: Supervised by a district
Classroom Activities: Provides support with academic activities under the direction of Licensed District Staff.	Classroom Activities: Provides support with academic activities under the direction of licensed staff.	administrator. Works under the direction of licensed staff, prepares materials for and supports the student who is deafblind.

Professional Learning Opportunities

Understanding Deafblindness and the Role of the Intervener Virtual Workshop – August 2024

Open Hands, Open Access Asynchronous Facilitated Cohorts with CEUs, begin mid-September 2024 for educators, educational interpreters, and trained interveners.







Contact Information and Thank you!

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