

Children with Combined Vision and Hearing Loss



TN Deaf-Blind Project

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Goals

- Increase your understanding of:
 - The Tennessee Deaf-Blind Project
 - Deaf-Blindness
 - Working with children who are Deaf-Blind
 - Resources available



Understanding Deaf-Blindness



Many faces of Deaf-Blindness



What is the Tennessee Deaf-Blind Project?



- The Tennessee Deaf-Blind Project (TNDB) is funded through the US Department of Education, Office of Special Education Programs.
- TNDB provides technical assistance, free of charge, to families, educators, and related service providers of individuals from birth through age 21 who have combined hearing and vision loss.
- A project that helps families and professionals improve outcomes for individuals who have combined vision and hearing loss (deafblindness)

Primary Activities



- Individual consultations at school, home, therapy, or community settings
- Workshops and conferences (ex. literacy, make and take)
- Practical strategies to deal with the unique sensory needs of children with combined hearing and vision loss.
- Assessments to determine ways to help children learn to communicate
- Educational and transition planning with families, students, and professionals
- Information and Referral
- Child find through Tennessee's census for individuals with combined hearing and vision loss
- Infant massage instruction

Who Benefits From Services?

- Individuals who have a combined vision and hearing loss (deafblindness)
- Parents, family members, and other care providers
- Educational personnel (e.g., early interventionists, teachers, service coordinators, speech-language pathologists, vision and hearing specialists, occupational and physical therapists)
- Health care, community, and state agency personnel

Who is eligible?

- Individuals who have mild to severe hearing and vision loss from birth through 21
- Individuals who have a diagnosis that places them at risk for developing both hearing & vision impairments (Usher Syndrome or Sticklers Syndrome, etc.)
- Individuals with multiple disabilities who demonstrate inconclusive responses during formal or functional hearing and vision evaluations

Who/What do you think of when you hear the term Deaf- blind?



Deafblindness: The Definition

“Deafblindness” means concomitant Hearing and Visual impairments, the combination of which causes such severe communication and other developmental and educational needs that they cannot be accommodated by addressing any one of the impairments.

TN DOE, Special Education Manual, Section Two, Chapter Six, *Understanding Disability Standards*, pg. 31.

.....they cannot be accommodated in special education programs solely for children with deafness or children with blindness

IDEA. 2004. Part 300. Subpart A. Section 300.8

Talking about Deafblindness

What does that mean?

- Although the term deafblind implies a complete absence of hearing and sight, in reality, it refers to children with varying degrees of vision and hearing losses.
- Neither sense can adequately compensate for the lack of the other
- The type and severity of losses differ from child to child.
- Even children who have the same condition causing their deafblindness will have very different amounts of usable vision and hearing and vary widely in ability.

Diversity in Deaf-Blindness



Some individuals have other disabilities in addition to vision and hearing loss.

Approximately 90% of children with deaf-blindness have one or more additional disabilities or health problems; 75% have two or more; 50% have three or more.

For children with complex needs, hearing and vision loss may not yet be recognized or addressed.



- Given less opportunities for functional movement and exploration
- Given less literacy experiences
- Lower expectations for learning and interaction

Leading Causes of Combined Hearing and Vision Loss

- Unknown Etiology
- Complications of Prematurity
- Hereditary
 - CHARGE Syndrome
 - Usher Syndrome
 - Down Syndrome
 - Trisomy 13
 - Norrie
- Prenatal/Congenital Complications
 - Cytomegalovirus (CMV)
 - Microcephaly
 - Hydrocephaly
 - Congenital Rubella
 - Herpes
 - Syphilis
 - Prenatal infant exposure to drugs or alcohol



Leading Causes of Combined Hearing and Vision Loss (cont)

- Postnatal Noncongenital Complications
 - Asphyxia
 - Meningitis
 - Severe Head Injury



“Red Flag” Medical Terms

- Anoxia, asphyxia, hypoxia
- Atresia
- Cerebral hemorrhage
- Cerebral Palsy
- Ischemia
- Meningitis
- Periventricular damage
- Fetal Alcohol syndrome

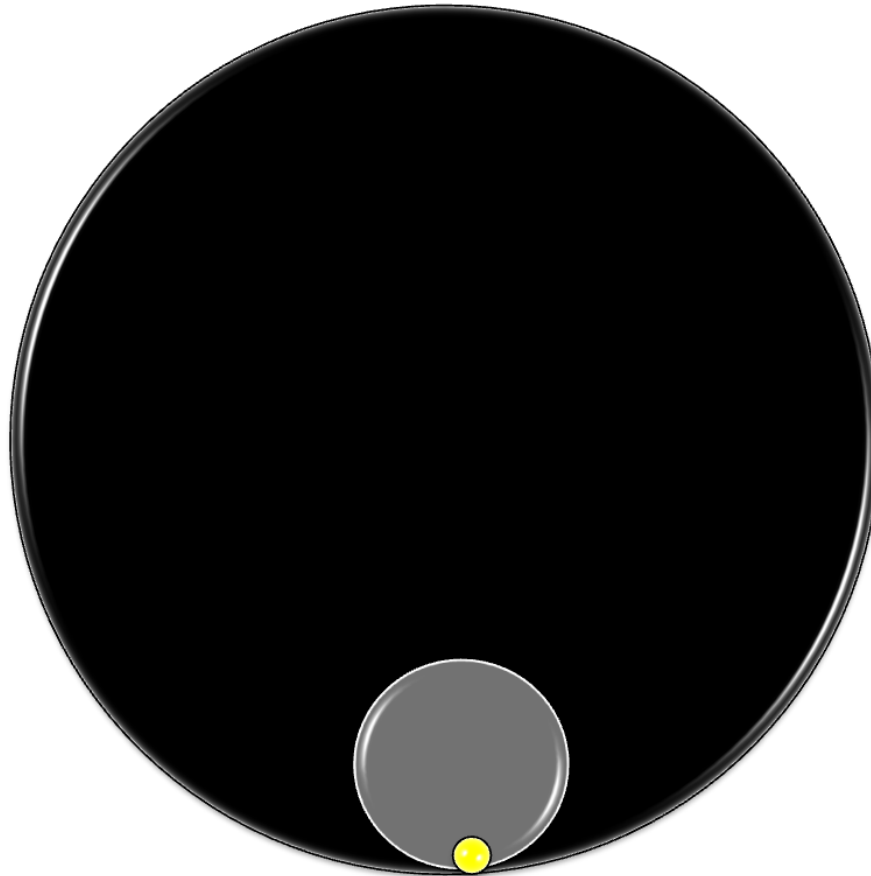


National Child Count

- Each state conducts a census of children and youth who are deaf-blind (birth through age 21).
- Information from all states is compiled and reported in the annual *National Child Count of Children and Youth who are Deaf-Blind*.



Population of Children With Deaf-Blindness: Birth-21

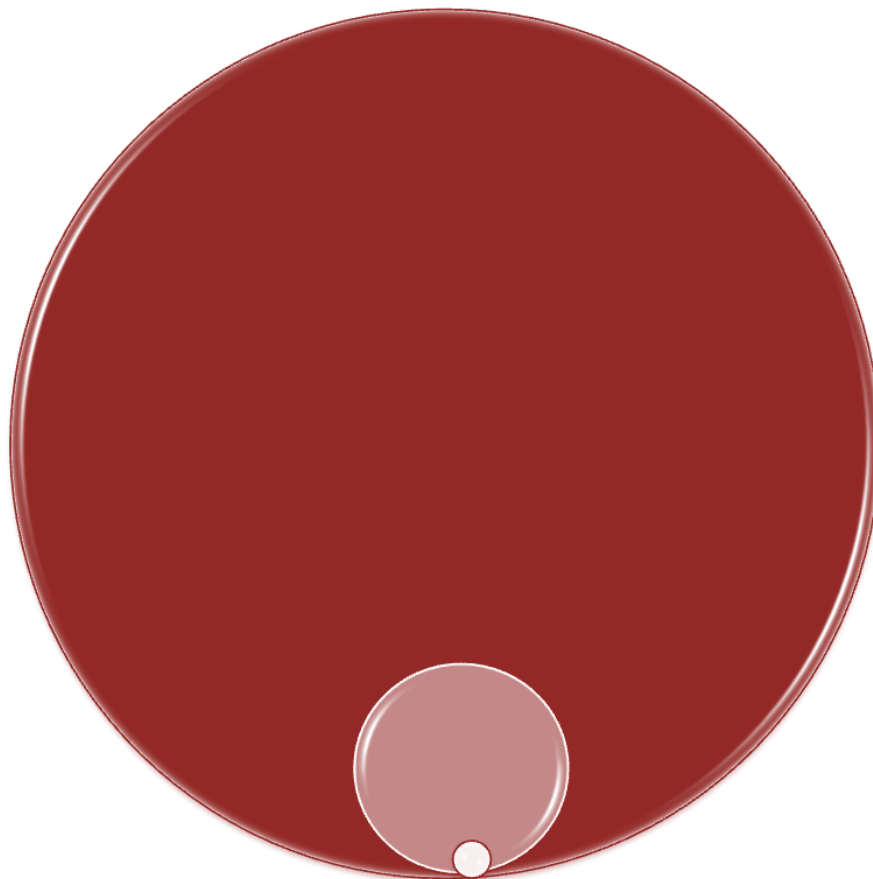


**Black circle: All children
age Birth-21 in the U.S.
(~87,877,000)**

**Grey circle: Children age
Birth-21 receiving
special education
(6,874,909)**

**Yellow circle: Children
age Birth-21 with deaf-
blindness (9,384)**

Population of Children With Deaf-Blindness: 0-2

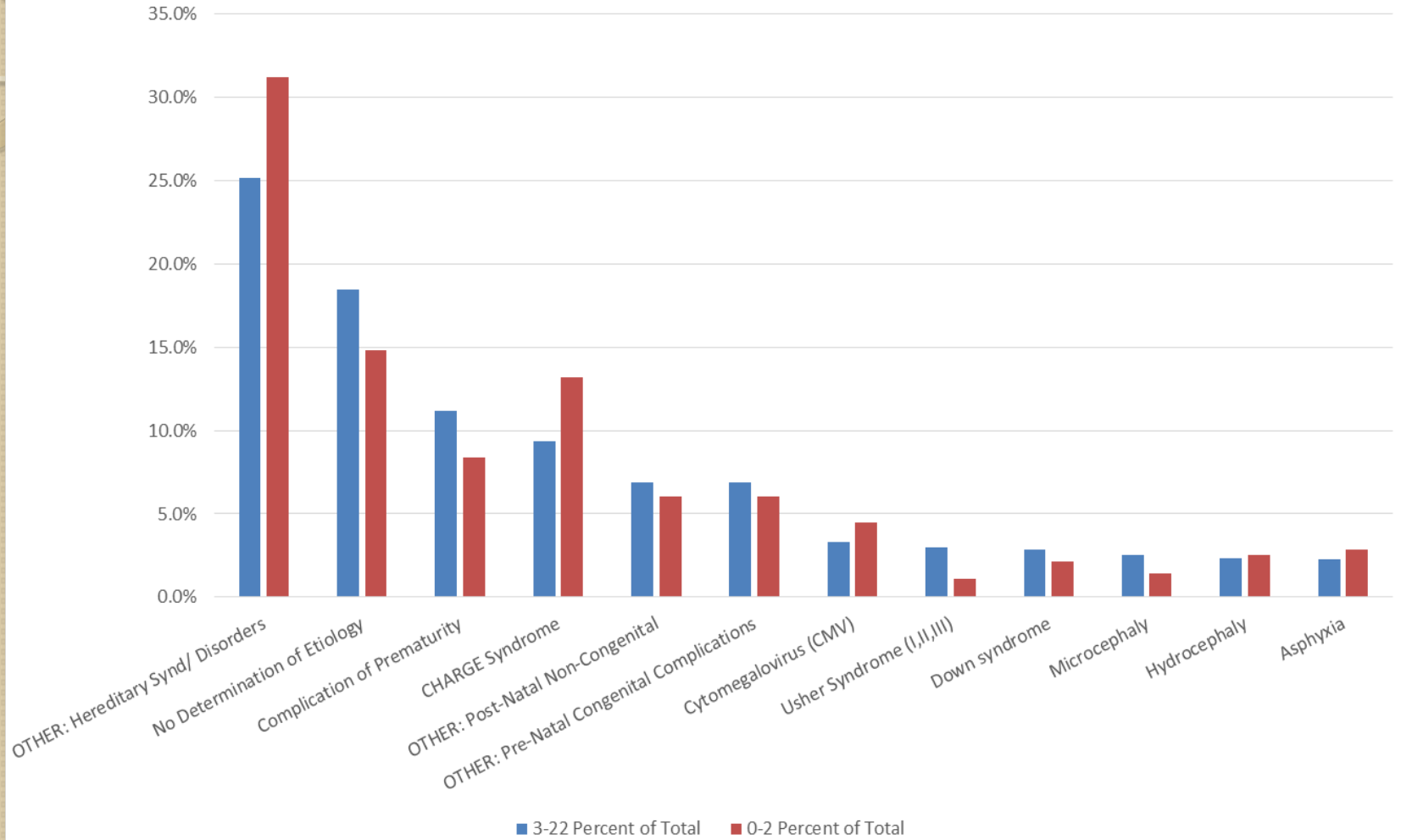


**Red circle: All children
age 0-2 in the U.S.
(~11,277,000)**

**Pink circle: Children age
0-2 receiving special
education (339,071)**

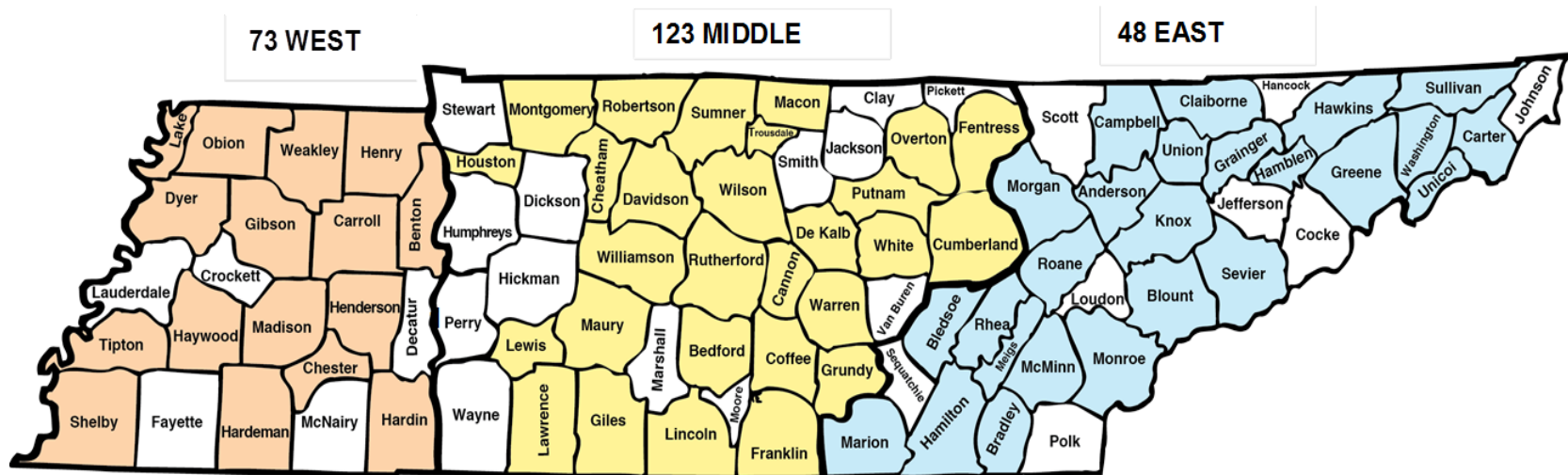
**White circle: Children
age 0-2 with deaf-
blindness (561)**

National Prevalence: Birth-21



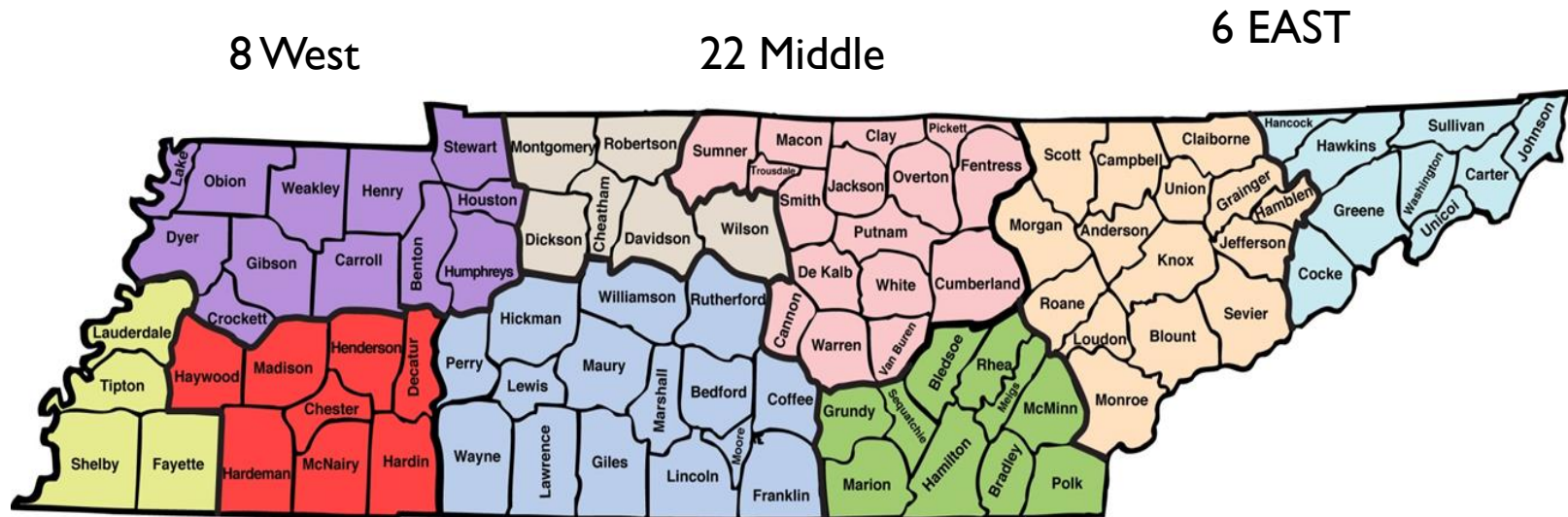
Tennessee's Deaf-Blind Census December 1, 2014

WHERE THEY LIVE 244 Children Birth to Twenty-Two



Counties that are colored white have no children reported.

Part C- 37 Identified Birth Through Two










8 West

22 Middle

6 EAST

Children Reported by TEIS District Offices

	#1 First TN	1		#4 Upper Cumberland	2		#7 Northwest TN	3
	#2 East TN	5		#5 Greater Nashville	11		#8 Southwest TN	3
	#3 Southeast TN	0		#6 South Central	9		#9 Memphis Delta	2

EAST 6

MIDDLE 22

WEST 8

Early Identification & Referral

It is recommended that children with one diagnosed sensory impairment (hearing or vision) be evaluated in the other area.

Referrals to medical and educational services should be made in a timely manner.

DO NOT “Wait and See”

Population of Children with Deaf-Blindness

- . Deaf-blindness is rare!
- . Providers often have limited experience working with children who are deaf-blind.
- . Families are often responsible for educating service providers about deaf-blindness and specifically about their child.

Deaf-Blindness is a disability...

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

How Do We Take In Information?

- **Through our distance senses:**
 - 83% visually
 - 11% hearing
- **Through our near senses:**
 - 3.5% smell
 - 1% taste
 - 1.5% touch



Excerpt from U.S. Department of Labor
Studies by educational researchers

80% of all Beginning Learning is VISUAL and AUDITORY

Motor patterns, concept development and social expectations are learned through watching and listening.

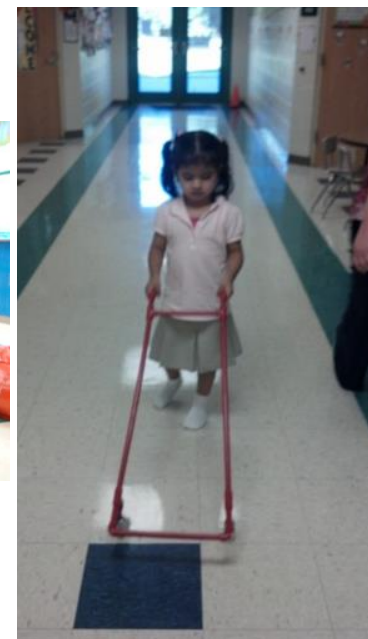


How Does a Child with Blindness Get Information About the World?



100% of beginning movement is visually motivated and enhanced by sound

- **Movement brings the child into contact with objects and people in the world**
- **If a child is restricted in movement, s/he will be restricted in information about the world**
- **Poor motor ability delays development of cognitive functions.**



Beyond Arm's Length



- **Social interaction**

All social skills are learned by observing and listening to the environment and people. Recognition of facial features and expression is socially more important than recognition of letters and numbers.

- **Communication**

Visual information in communication and social interaction is low contrast level and in motion! Children with sensory impairments will not recognize social body language or gestures without direct instruction.

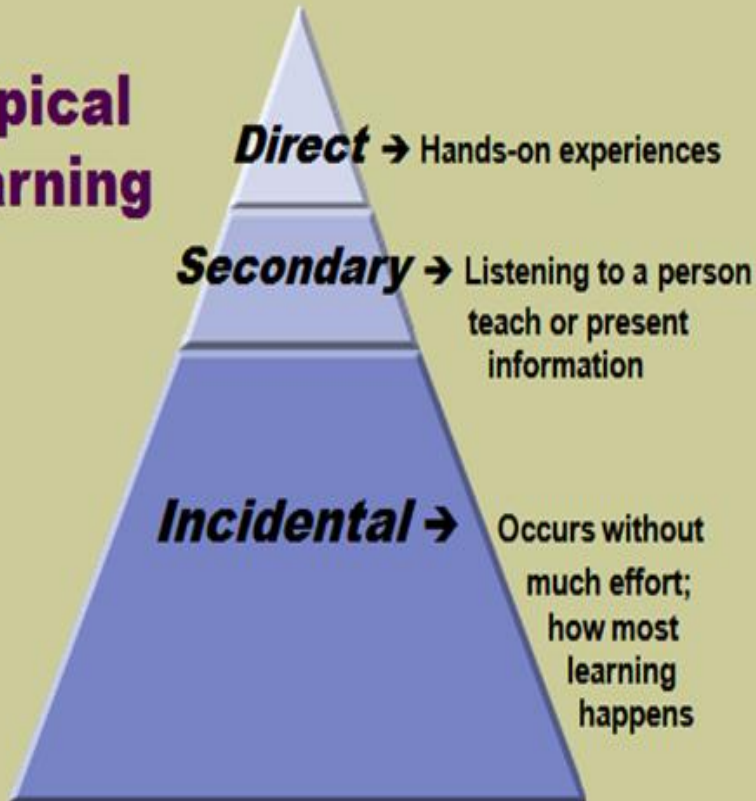
- **Incidental Learning**

Incidental learning occurs through observation and independent exploration of materials. Early Childhood classrooms are designed to encourage incidental learning (centers, circle time). Children with dual sensory impairments do not learn detailed information from observation; they need supervised discovery of classroom materials.



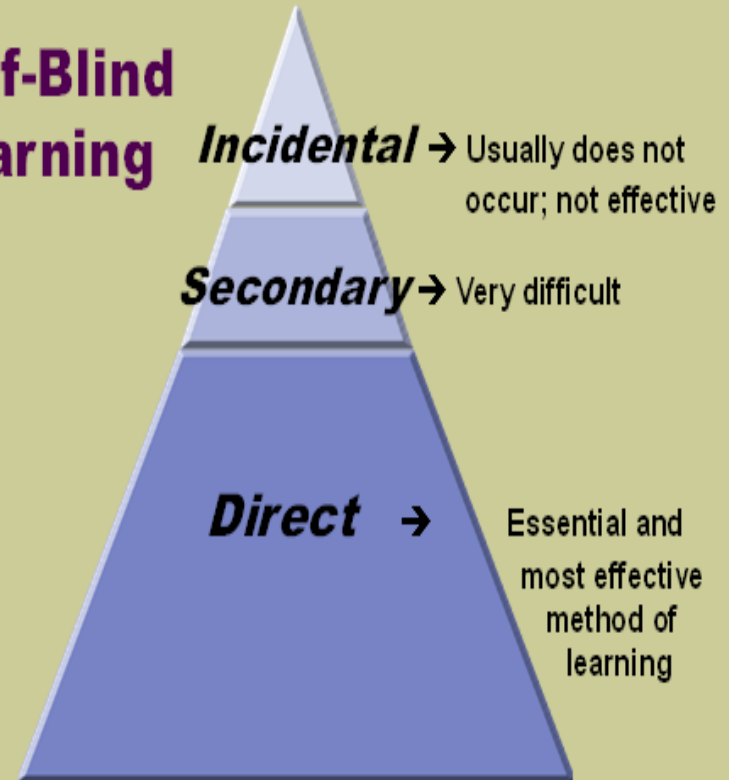
Sensory Challenges turn learning upside down!

Typical Learning



Alsop, L., 2009

Deaf-Blind Learning



Alsop, L., 2009

Learning Needs of Children with Deaf-Blindness

- Hands-on experiences
- Active movement and exploration of their environment
- Predictable, accessible schedules, consistency
- Use of residual hearing and sight
- High expectations
- Trusting relationships
- Communication, communication, communication!



Implications for Intervention

Communication

Touch

Environmental Considerations

Social/Emotional

Concept Development






COMMUNICATION

- SLOW DOWN
- Children don't start thinking until you stop talking

Principles for Making Contact and Communicating

- Approach effectively and make introductions
- Respect behavior as communication
- Follow the person's lead and interests
- Acknowledge by touch and imitation
- Give time to respond
- Be as unobtrusive as possible
- Use cues to allow for anticipation
- Interpret the environment

- 
- Interpret the environment
 - Allow the learner the opportunity to make choices in an activity
 - Use cues to allow for anticipation
 - Use to touch cues
 - Use object cues
 - Always let the learner know when you are leaving

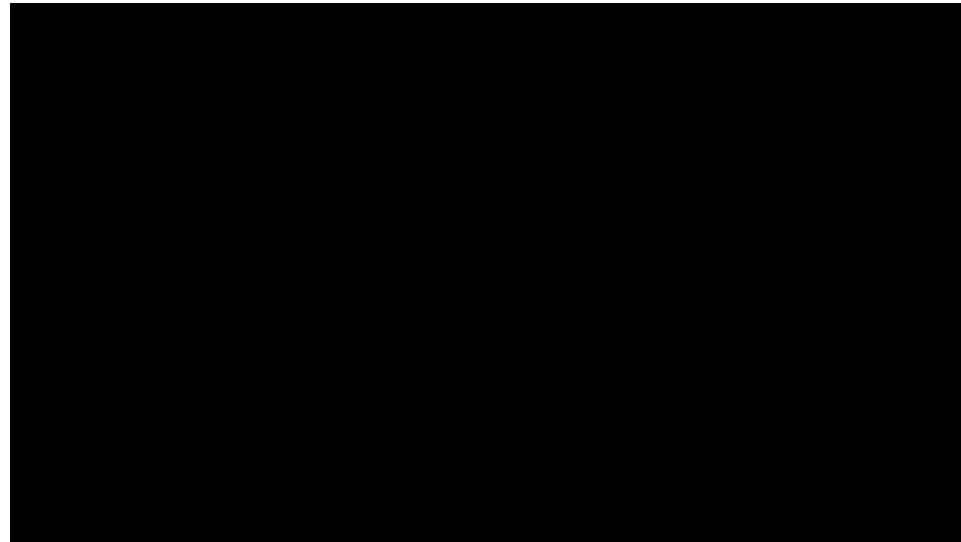
Communication

- Multi-modal communication
 - Objects
 - Coactive signs
 - Signals and cues
 - Calendar systems
- Say it, sign it, touch it
- Wait time
- Watch entire child

Communication

- Children who are deafblind miss opportunities to:
 - Observe the communication of others
 - Participate in communication themselves
- Communication attempts may be missed or misunderstood

Communication and Expression



Shared Modes of Communication

- The mode of communication you use must be accessible to the child
- Model communication using shared modes
- Provide for incidental learning through access: allow the child to observe conversations in his/her shared mode

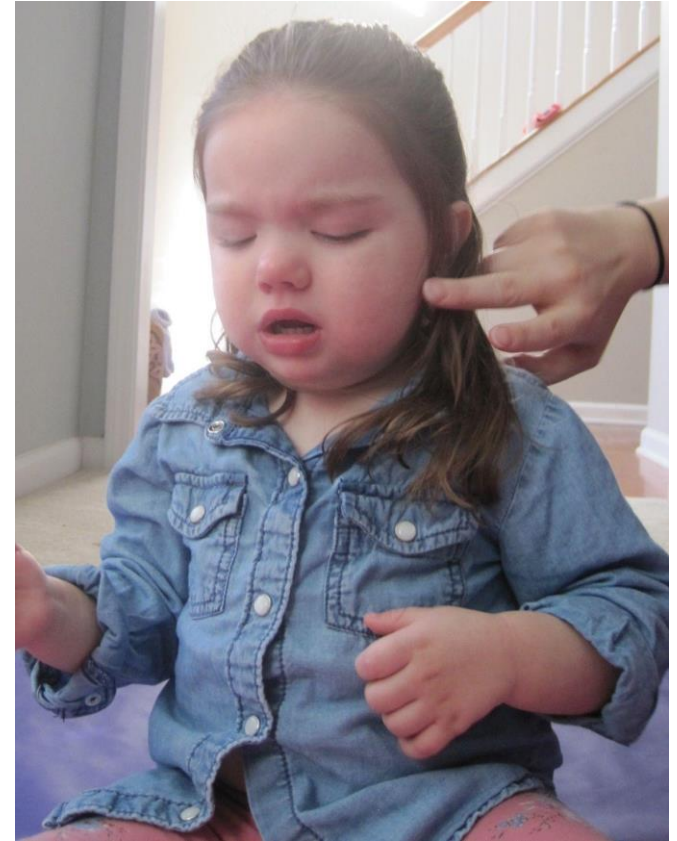
What is a Touch Cue?

A TOUCH CUE consists of
tactile contact,
made in a consistent manner
directly on the learner's body,
to communicate with her.

Why use Touch Cues?

The **PURPOSE** of a touch cue is to **communicate** who is there and what's going to happen.

May reduce a learner's startle or challenging behaviors, by helping her anticipate what is going to occur.



Examples of Touch Cues

- Tapping the child's bottom (in supine)- "I'm going to lift your hips" (for diaper)
- Gently pulling up on the child's upper arms - "Get ready to stand up."
- Touching the child's left elbow - "This is the way I say 'Hi,' so you know who I am."
- Touching the child's ear- "Time to put your hearing aids on."

Interactions with Touch



- All human beings require tactile input
- Research shows that positive “touches” are correlated with good physical and mental health
- Touch assists learners with deaf-blindness to come out into the world and engage with a partner



Environmental Considerations

Changing the environment to help the child change

Lilli Nielsen

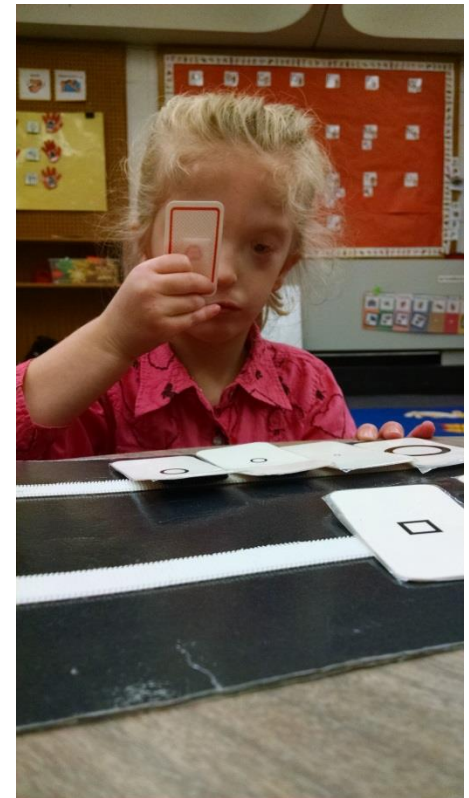


Environmental Considerations

- Visual (Contrast, Size, Lighting)
- Auditory (Background noise, Acoustics)
- Other Sensory Input- Tactile, Olfactory, Taste, Proprioceptive, Vestibular
- Physical space- is the arrangement meeting the needs of the child?
- Maximize the child's use of residual vision and/or hearing

Assessment of the Tactile Environment

- How / when does the learner have physical contact with others? How does the learner respond to these physical interactions?
- How / when does the learner have an opportunity to touch, explore, handle, and use materials?



Assessment of the Tactile Environment



- How is the environment arranged / organized to encourage tactile exploration and movement?
- What adaptations might better facilitate the learner's exploration, handling, and manipulation of objects?

(Chen & Downing, 2006, pp. 55 & 57)

Social Emotional

- Encouraging Relationships and Bonding
- Fostering Trust
- Stress
- Intervener Support

Building Rapport



- Approach child from side
- First point of contact: shoulder or leg, not hands
- Use voice, personal identifier, or touch to identify yourself
- Wait for acknowledgement, allow child to turn, reach, connect

Building Rapport

- Make yourself available, move slowly
- Provide wait time
- Observe child for communication attempts:
 - movements
 - muscle tension
 - change in posture
 - eye gaze
 - vocalizations
 - gestures
- Respond through turn taking

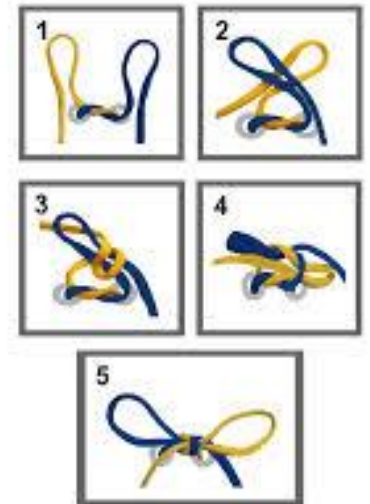
Concept Development

“Concepts are the ideas that give meaning to our world. We develop concepts based on our particular experiences.”



Concepts vs. Skills

- A *skill* is the *ability* to do something – for example: tying a shoe, using vision to find an object, clean a table
- A *Concept* – the ideas that help us understand “why”



Concept Development

- Concepts vs. Skill
- Concepts
 - Concrete concepts (i.e. chair)
 - Semi Concrete concepts (i.e jumping)
 - Abstract Concepts (i.e. nervousness)
- Concepts
 - People and Relationships
 - Objects
 - Places
 - Routines, Actions, and Activities

Concept Development- Objects



- Objects exist
- Objects have permanence
- Objects differ
- Objects have names or labels
- Objects have characteristics
- Objects have functions or use

Concept Development

- Essential information is missed and incidental learning is greatly limited
- All individuals have an “ongoing struggle to obtain information.”

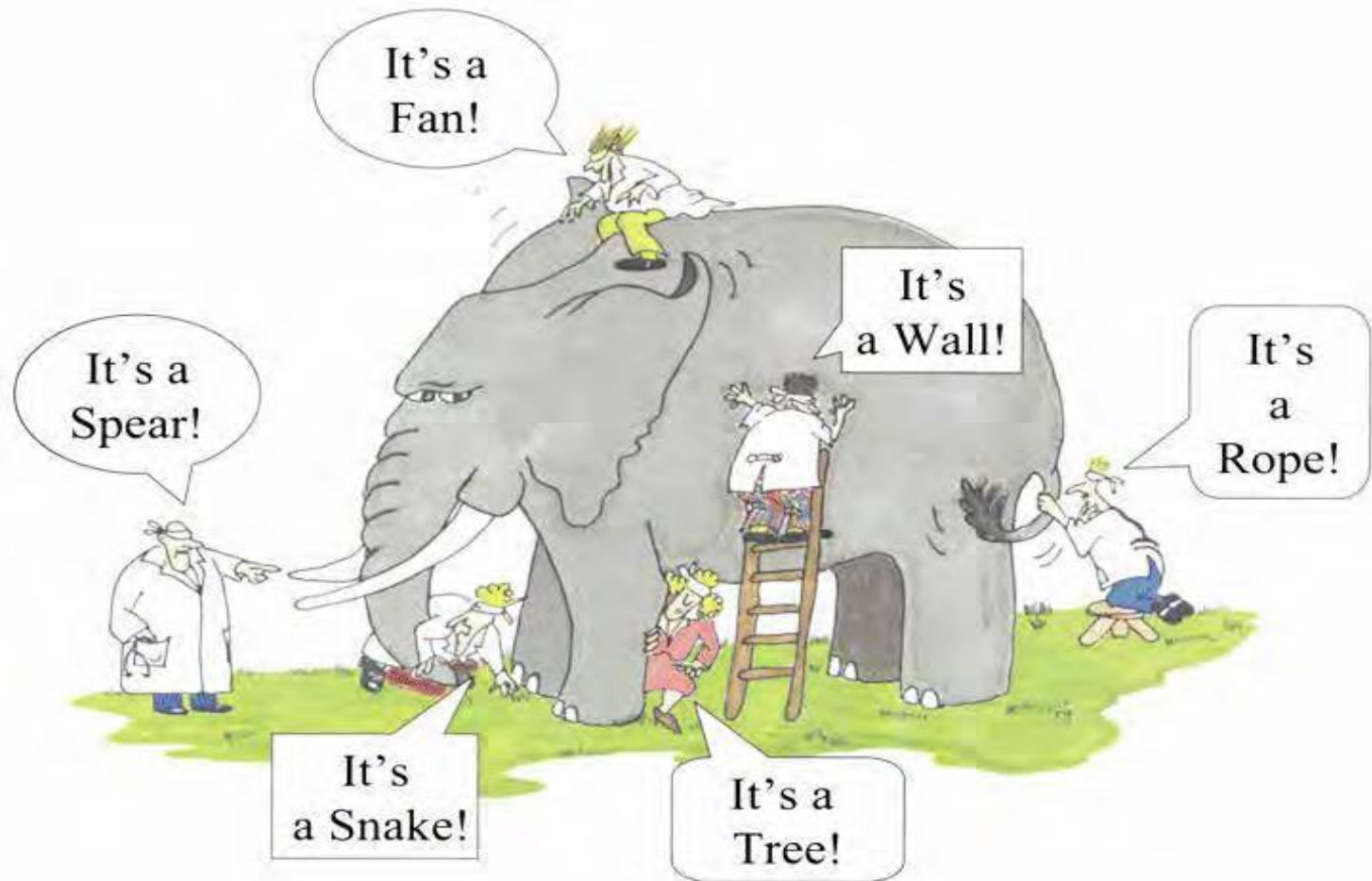


Concept Development

- Children need:
 - Hands on experiences
 - Shared experiences
 - Thoughtful presentation of experiences that “enable them to develop a gradually expanding view of the world.”
 - Information, materials, and experiences presented in multimodal formats



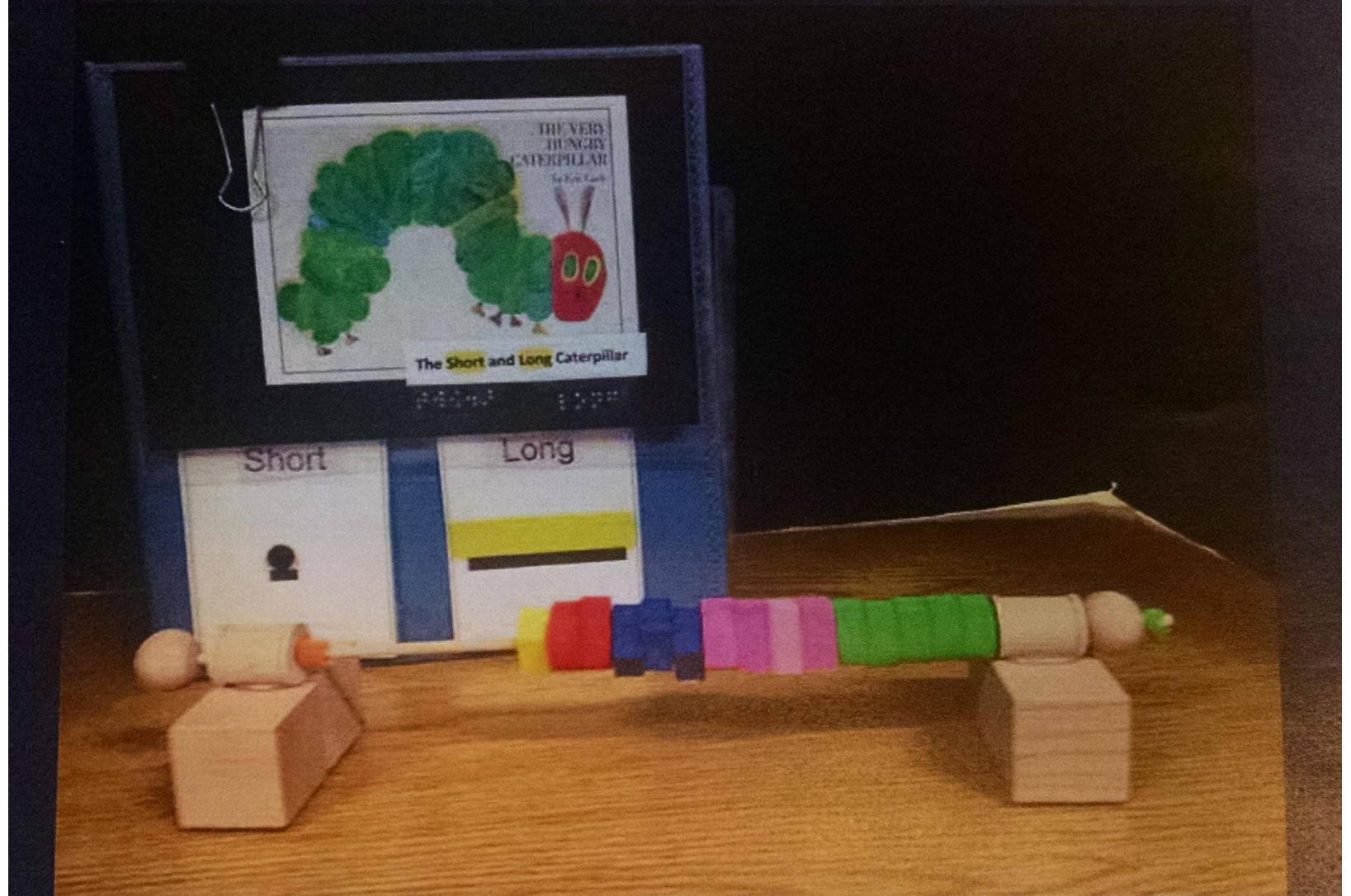
What happens to concept development when we have limited experiences?



How to choose a concept to work on

- • Start with the child in mind.
- • What is meaningful to the child right now?
- • What is something that might help the child participate in day to day life?
- • What is something that would help the child understand the world around her/him better?
- • Remember, this should be a team approach

Concept book for "long/short"



Concept book for "wet/dry"

5 little, dry frogs,
Sitting upon a log.
Eating some most delicious flies.
Yum, yum!

One jumped into the pool,
Where it is nice and cool,
But now he's dripping wet.
Oh no!



5-1
Count
on hand

dry



sit



eat



y





Long Wavy Grass



Thick Oozy Mud



A dark gloomy cave

Points to Remember

- Deafblindness is varied and complex
- Children with deafblindness are as diverse as the number of children reported
- Early identification and intervention are **essential**
- Children and youth who are deafblind often have other disabilities
- Training and support are available through TNDB which is a federally funded technical assistance project.

Resources:

- National Center for Deaf-Blindness
 - www.nationaldb.org
- Texas School for the Blind and Visually Impaired
 - www.tsvbi.edu/outreach/deafblind/index.htm
- WonderBaby
 - www.wonderbaby.org
- Perkins School for the Blind
 - www.perkins.org
- American Printing House for the Blind
 - www.aph.org

- CHARGE Syndrome Foundation
 - infor@chargesymdrome.org
- Hellen Keller National Center
 - hkncinfo@hknc.org
- National Family Association for Deaf-Blind
 - www.NFADB.org
- All children can read...let us show you how!
 - <http://lieracy.nationaldb.org>

OHOA Deaf-Blind Intervener Learning Modules

A national resource designed to increase awareness, knowledge, and skills related to the process of intervention for students who are deaf-blind. Developed by National Center on Deaf-Blindness.

For a list of partners and contributors visit:

nationaldb.org/ohoamoodle/contributors.html

For more information:

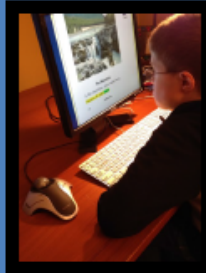
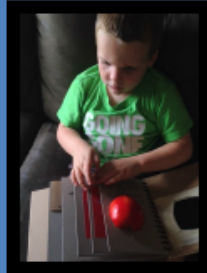
Go to nationaldb.org/ohoamoodle/ or

contact Amy Parker, Ed.D, parkera@wou.edu



Literacy Starts with Communication!

<http://literacy.nationaldb.org>



Did You Know?

- Communication and social interaction go hand in hand with learning literacy
- Literacy begins at birth and develops through rich experiences with in the environment
- Your child can read and write in a variety of ways such as: tactile objects, symbols, pictures hands and electronic devices
- All children should have access to rich literacy activities.

What will your family gain?

- An understanding of the stages of communication and literacy development
- Ideas for activities that can be used in your home, school and community
- Through a coordinated effort with your child's educational team your child will have positive and effective experiences with learning communication, reading and writing.

What you will find?

- The "How-to's" of communication and literacy development for children with significant learning needs, including deaf-blindness.
- The "Literacy Skills Checklist" that will show your child's success and help support literacy activities.
- Practical examples from families and classrooms
- Extended resources for building literacy

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More information about deaf-blindness at National Center on Deaf-Blindness nationaldb.org and nationaldb.org/families



TN Deaf-Blind Project



If you would like to refer or child, interested in us providing a training or need more information please contact us!

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