



**National Center  
on Deafblindness**

# **The Role of Collaborative Partnerships in Newborn Screening and Identification: *Supporting Deafblind Infants and their Families***

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# In this session you will learn...

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- **Examples of successful state level partnerships that highlights the benefits of early identification of vision status**
- **Identify common risk factors and etiologies associated with deafblindness**
- **Examples of family perspectives of successful collaborations that improve services and supports for their children who are deafblind**

# Welcome!

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- Who is in the room?
  - Role
  - State
  - Why are you here today?

# Simulation

# **Moment to Reflect and Reset**

# Maybe it's right in front of us!

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<https://www.youtube.com/watch?v=Ahg6qcgoay4>



# What does DeafBlind look like?





# What does DeafBlind look like?





# What is Deafblindness?

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- Combined Vision and Hearing Loss of any level
- Combination of distance senses = deaf TIMES blind
- Lowest of the low incidence disabilities
- Approximately 10,000 children birth - age 22 in the US
- Approximately 87% have additional disabilities
- Disability of access
- [2022 National Deafblind Child Count](#)

# Lesson 1: An Introduction to Deafblindness

## Range of Combined Vision and Hearing Loss in Deaf-Blindness

The shaded cells represent areas of combined vision and hearing loss. Cells with no shading indicate that either vision or hearing is within normal range.

		Degree of Vision Loss and Related Conditions						
		Mild or No Visual Impairment (20/40 to 20/70)	Moderate Visual Impairment or Low Vision (20/70 to 20/200)	Severe Visual Impairment or Legal Blindness (20/200 to 20/400 or visual field <20°)	Light Perception Only	Total Blindness	Diagnosed Progressive Loss	Cortical Visual Impairment (CVI)
Degree of Hearing Loss and Related Conditions	Normal -10 to 15 dB							
	Slight 16 to 25 dB							
	Mild 26 to 40 dB							
	Moderate 41 to 55 dB							
	Moderately Severe 56 to 70 dB							
	Severe 71 to 90 dB							
	Profound 91 dB or greater							
	Central Auditory Processing Disorder (CAPD)							

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# Causes of Deafblindness

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- Unknown Etiology
- Complications of Prematurity
- Hereditary
  - CHARGE syndrome
  - Stickler syndrome
  - Dandy-Walker syndrome
  - Usher syndrome
  - Down syndrome
- Prenatal/Congenital Complications
  - cCMV
  - Microcephaly
  - Hydrocephalus
  - Prenatal exposure to drugs or alcohol
- Postnatal/Non-Congenital
  - Lack of oxygen
  - Birth Complications
  - Meningitis
  - Trauma to the brain

# Risk Factors for Vision Loss

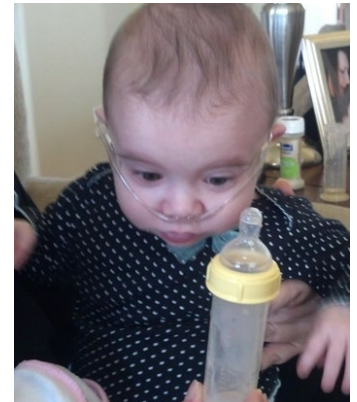
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- Family member concerned about vision
- Baby was exposed to alcohol or drugs before birth
- Baby was premature and given oxygen in the hospital
- Baby had birth weight of less than 3.3 pounds.
- Child had meningitis or encephalitis.
- Mother had infection (toxoplasmosis, rubella, CMV, syphilis, herpes) during pregnancy.
- Family history of vision loss (retinitis pigmentosa).
- Child has neurological problems, such as seizures
- Child has other medical concerns (hearing loss, cerebral palsy).

# Cerebral/Cortical Visual Impairment

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- Leading cause of visual impairment (40%) and DeafBlindness (50%)
- Visual loss caused by neurological issues and diagnosed by etiologies, cluster of specific behavioral or visual responses, and caregivers' observations
- First three years are most critical
- CVI affects vision, hearing, balance/movement, and executive functioning
- **Treatment is educational, not medical**



# CVI Stats and Complex Profiles



<b>82% of Infants with CVI have strabismus and/or refractive errors</b>		<b>40% of all children with CVI were premature</b>	
<b>Seizure disorder</b>	<b>50%</b>	<b>Developmental Delays</b>	<b>10.5%</b>
<b>Hypoxic ischemic encephalopathy (HIE)</b>	<b>40</b>	<b>Periventricular leukomalacia (PVL)</b>	<b>58%</b>
<b>Microcephaly</b>	<b>90%</b>	<b>Cerebral vascular accident</b>	<b>14%</b>
<b>Hydrocephaly</b>	<b>58%</b>	<b>Cytomegalovirus (CMV)</b>	<b>20%</b>
<b>Encephalitis</b>	<b>15%</b>	<b>Meningitis</b>	<b>15%</b>
<b>Down Syndrome</b>	<b>38%</b>	<b>Cerebral Palsy</b>	<b>70%</b>
<b>Optic Nerve Hypoplasia</b>	<b>60%</b>	<b>Autism Spectrum Disorder (ASD)</b>	<b>15%</b>
<b>ADHD</b>	<b>16%</b>	<b>Learning Disabilities</b>	<b>11%</b>
<b>Developmental Delays</b>	<b>15%</b>	<b>Traumatic Brain Injury</b>	<b>50%</b>



# Typical Vision Development (1 of

2)

- 1 month: Looks at mothers or caregivers face. Responds to lights.
- 2-4 months: Begins to smile at others. Follows a moving person with his/her eyes. Fascinated by lights and bright colors. Begins to look at own hands.
- 5-8 months: Watches things happening across the room. Reaches for nearby toys. Looks at small objects, such as raisins or small cereal.

# Typical Vision Development (2 of 2)

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- 9-12 months: Reacts to facial expressions of others. Looks for fallen toys, even around corners. Is interested in picking up tiny objects, such as lint on carpet.
- 12-18 months: Marks and scribbles with a crayon. Interested in picture books. Can reach in and pull out objects easily. Builds a short tower with blocks.
- 1½ -3 years: Sees detail in familiar pictures. Copies a circle with a pencil or crayon. Looks for familiar things in the distance. Can imitate movements of others. Matches objects to pictures.

# Risk Factors for Deaf/hard of hearing

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- Family concern about child's hearing.
- Baby was in NICU for 3 days or more, or was given oxygen for 10 days or more.
- Baby had unusual ear, head or neck formation.
- Baby had birth weight of less than 3.3 pounds.
- Baby had severe jaundice and an exchange blood transfusion was recommended.
- Mother had infection (toxoplasmosis, CMV) during pregnancy.
- Child has had an injury or trauma to the head.
- Child had meningitis
- Family history of hearing loss.

# Typical Listening, Speech, & Language Development (1 of 2)

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- 0-4 months: Startles to loud sounds. Quiets to the sound of a familiar voice.
- 4-6 months: Turns toward or looks for a familiar or new sound. Likes rattles and objects that make sound.
- 6-12 months: Turns or looks up when called by name. Imitates sounds and pitches. Understands the meaning of simple words and phrases, such as no and bye bye. Uses voice to get attention.

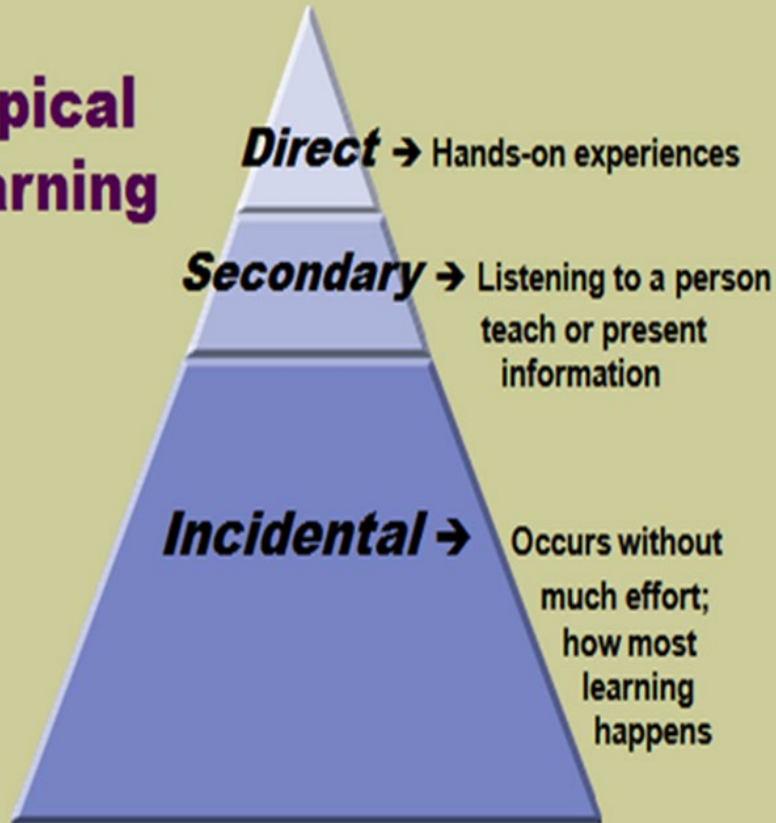
# Typical Listening, Speech, & Language Development (1 of 2)

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- 12-18 months: Uses 4-5 words by 18 months. Points to at least one body part when asked. Understands one-step instructions, such as Get me your diaper, or Close the door.
- 18-24 months: Uses 10-15 words and puts 2 words together by age 2 years. Likes music. Points to familiar objects when you name them.
- 2 -3 years: Uses 200 words by age 3 years. Listens to radio or TV at the same loudness as other people. Hears when called from another room. Uses 2-3 word sentences. Strangers can understand most of your child's speech.

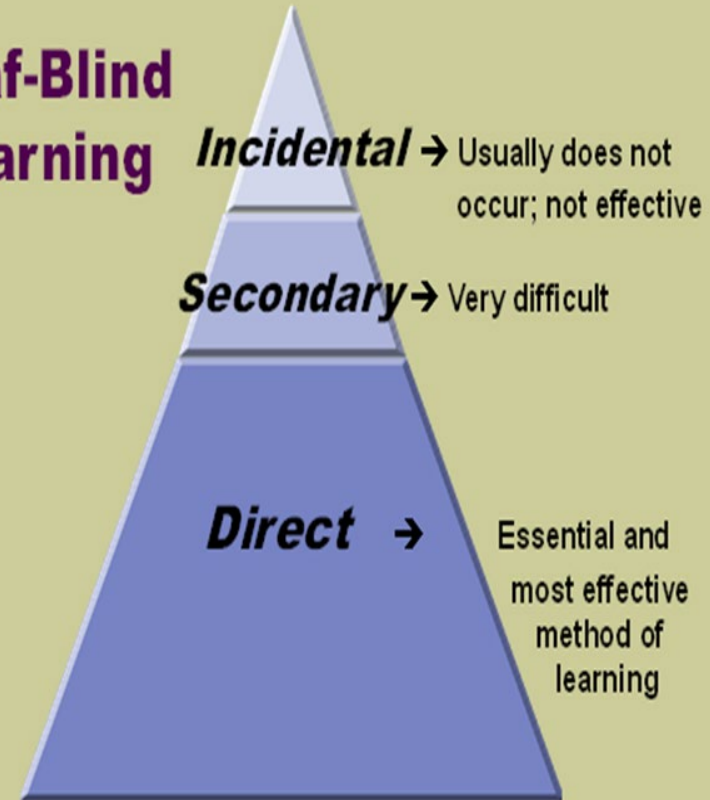
# DeafBlind Learning Pyramid

## Typical Learning



Alsop, L., 2009

## Deaf-Blind Learning



Alsop, L., 2009

# Robert Video - Active Learning

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<https://nam04.safelinks.protection.outlook.com/?url=https%3A%2F%2Flibrary.tsbvi.edu%2FPlayer%2F67642856&data=05%7C02%7Cdonna.carpenter%40uky.edu%7Cce828053a92246b42e2b08dc45fa329c%7C2b30530b69b64457b818481cb53d42ae%7C0%7C0%7C638462188115204697%7CUnknown%7CTWFpbGZsb3d8eyJWIjoiMC4wLjAwMDAiLCJQIjoiV2luMzIiLCJBTiI6Ikk1haWwiLCJXVCI6Mn0%3D%7C0%7C%7C%7C&sdata=a%2BpZK%2Bm2Eie2Xl6%2FtEviNw12300DwuCdKzNT%2F9RsL6I%3D&reserved=0>



# Why Refer?

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- Children who are DeafBlind require specialized teaching strategies to help access their environment to learn
- Referral to your state deafblind project can support children with deafblindness and their families across environments to learn these skills strategies
- Training & resources can provide providers and families tools to:
  - Help young children learn how to access residual vision and hearing
  - Learn skills to support the child's learning, communication, social emotional development, motor development and increase independence

# Babies Grow Up to Be Adults!

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# State DeafBlind Projects Provide

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Individual, on-site consultations at school, home, or in the community

Resources, support and information related to dual sensory loss

Instructional strategies to address the unique communication and learning needs of each individual child

Workshops, training, conferences targeting issues related to specific deafblind areas for parents, families, and professionals

Guidance through transitional periods: early childhood transitions to school; transition from one classroom or school to another; and transition into adulthood

Opportunities for families and professionals to network

Child Find and maintain a state census of individuals birth through age 21 with combined hearing and vision loss

# Contact Information for Your State Deafblind Project

# What Can You Do?

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- If you suspect that your child or a child you work with may have combined vision and hearing loss:
  - Contact your State or Multi-State Deaf-Blind Project
    - [Contact your State Deafblind Project](#)
    - Provide resources, consultation, training, and networking opportunities for families & professionals
    - Serve Birth - Age 21
  - Resources & Information: [National Center on Deaf-Blindness](#)
  - Funded by the Office of Special Education Programs

# Importance of Collaboration

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We're better together!

- Partnering is critical because of limited time and funding
- We share these families so knowledge around suspected combined vision and hearing loss is critical for identification and referral
- Early ID leads to better services and supports for families

# Sarah Streeval's Story

<https://youtu.be/Tz9xWKAY>

[hIA](#)



# Rey and Nelleke's Story

<https://youtu.be/DEEDVFruqGo>

**Check In**

**Break**

# Simulation

# **Moment to Reflect and Reset**

Sarah Roof - KY Hands & Voices

<https://youtu.be/dsILyWsFJ>

Oc

Add Lori Travis and Jeanne Albano

[https://youtu.be/MM\\_gjjSGwOU](https://youtu.be/MM_gjjSGwOU)

# Minnie Lambert

“What did services look like for you and your family?”





**Check In**

# Where Do We Go From Here?

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- Individual Think Time
  - A takeaway from the family and provider stories
  - One piece of information that will inform your practice
  - A concrete next step to advance your collaborative partnerships in your state
  - One thing you are still wondering or need additional information about
- Table Sharing
- Large Group Report Out

# More Deafblind Sessions at EHDI!

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# Why We All Do What We Do



## Lunch and Learn

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# “I love, Momma”

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# Contact Us!

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- Donna Carpenter, Kentucky DeafBlind Project:  
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[rhill@scsb.org](mailto:rhill@scsb.org)

# References

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# National Center on Deafblindness



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