



**National Center  
on Deafblindness**

# **The Deafblind Child Count: Key Ways to Collaborate to Identify Infants who are Deafblind**

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# Outcomes

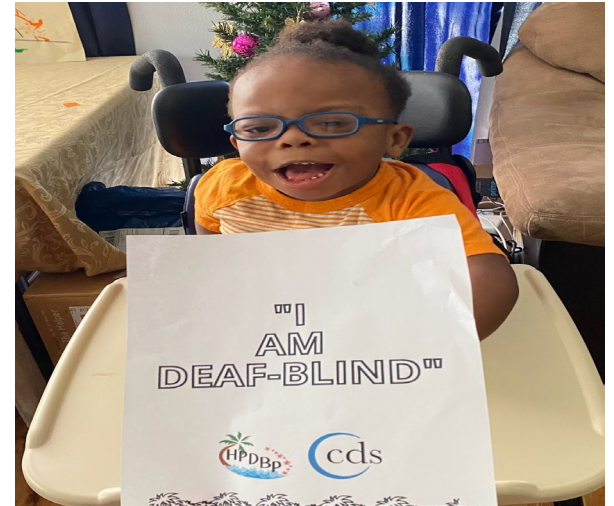
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Participants will:

- Increase knowledge of the under identification of infants and toddlers through observing and comparing the national deafblind child count data and other data sources
- Identify what activities and collaborations could be pursued in their states to improve identification of deafblind infants and referral to state deafblind projects

# Deafblindness (1 of 2)

- Most diverse and complex disability
- Combination of hearing and vision loss
- Most children (99%) have some useable vision and/or hearing
- Varies from person to person
- Many individuals who are deafblind share similar needs



# Deafblindness (2 of 2)

- A disability of access
- Necessary to provide consistent and responsive, specialized support
- Lack of access to incidental learning
- Deafblindness is a continuum
- Unique communication, learning, and mobility challenges



# What is the Child Count?

- Began in 1986: [2024 National Child Count of Children and Youth who are Deafblind & Child Count Page](#)
- Provides information on the population of children identified as deafblind in the U.S., ages birth through 21
- 11,214 children in the U.S., ages birth-21, have been identified as deafblind.



# 2024 Deafblind Child Count (1 of 2)

- 55% have complex healthcare needs
- 94% have one or more additional disabilities
- Some children are born with their disability, while others lose their vision and hearing over time.



# 2024 Deafblind Child Count (2 of 2)



- Only about 3% of children with deafblindness have both profound hearing loss and total blindness.
- 4% are totally blind
- 30% had Cortical Visual Impairment (CVI)

# Top Etiologies of Deafblindness

Age	0-3	6-12
CHARGE syndrome	121	417
Down syndrome	28	147
Usher syndrome	52	176
Other hereditary syndromes	222	858
CMV	32	136
Other Prenatal Complications	73	236
Complications of prematurity	68	271

# Deafblind Children Ages 0-2

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Age	Total Children who are Deafblind
0 - 1	70
1-2	214
2-3	338

# Potential Identification Challenges

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- Misunderstanding around the term “deafblind”
  - Identification of vision loss, Deaf/hard of hearing
  - Identification of child as deafblind
- Delays between diagnosis, referral, and services
- Assumptions on family readiness

# Innovative Partnerships

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- Data Sharing Memorandums of Understanding
- Partnership Agreements
- Networking and Collaboration Activities
- Work Groups
- Part C & EHDI Data Sharing Agreements & Resource Documents from Early Childhood Technical Assistance Center (ECTA)

# It Takes a Village!

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- 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
- We're better together!

# Helpful Next Steps

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- Check out your [state's data](#)
- Make connections with your [state deafblind project](#)
- NCHAM trainings on deafblindness:
  - [Webinar](#), [Coffee Chat: Data](#), [Coffee Chat: Minnesota](#)
- Reach out to share feedback about additional resources, training and supports that might be helpful to you  
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# National Center on Deafblindness



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