

# Under Identification of Infants and Toddlers with Deaf-Blindness

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National Center on Deaf-Blindness

# Purpose

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To provide an overview of:

- The Deaf-Blind Technical Assistance network
  - National Center on Deaf-Blindness
  - State Deaf-Blind Projects
- The National Child Count

To discuss:

- Under identification of infants and toddlers with deaf-blindness
- Under referral of infants and toddlers with deaf-blindness
- Strategies to address under identification

# Session Objectives

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## Objectives:

- Participants will increase knowledge of common etiologies & risk factors associated with deaf-blindness.
- Participants will increase their knowledge of systems strategies to increase the identification and referral of children who are deaf-blind.
- Participants will increase their knowledge of the reasons why referral to state deaf-blind projects is important for children who are deaf-blind and their families.

# Deaf -Blind TA Network

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- National Center on Deaf-Blindness (NCDB)
  - TA to state projects and a range of national partners including family organizations
- State Deaf-Blind Projects
  - Provide free technical assistance to families, educational teams and service providers of children birth through the year of their 21st birthday, if the children have a combined vision and hearing loss, or are highly suspect for both vision and hearing loss.
  - A range of family activities and supports

# NCDB Initiative Areas

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- Identification and Referral
- Family Engagement
- Interveners & Qualified Personnel
- Transition to Adult Services
- National Child Count

# Deaf -Blind Projects Provide (1 of 2)

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- Resources and information related to supporting the learning and development of children with deaf-blindness (for families, providers & educators)
- Individual, on-site or virtual consultations at school, home, or in the community
- Workshops, training, and conferences for parents, families, and professionals targeting
  - Family support, learning, and networking opportunities, educator and provider professional development

# Deaf -Blind Projects Provide (2 of 2)

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- Guidance through transitional periods: early childhood transitions to school; transition from one classroom or school to another; and transition into adulthood
- Financial support for participation in training opportunities
- Opportunities for families and professionals to network
- Child Find and maintain a state child count of individuals birth through age 21 with combined hearing and vision loss

# Overview of Deaf -Blindness (1 of 2)

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- When we hear the term “*deafblind*”, we often imagine a person who is unable to hear or see anything, such as Helen Keller.
- “Deafblindness” refers to combined hearing and vision loss, representing a wide range of vision and hearing levels.

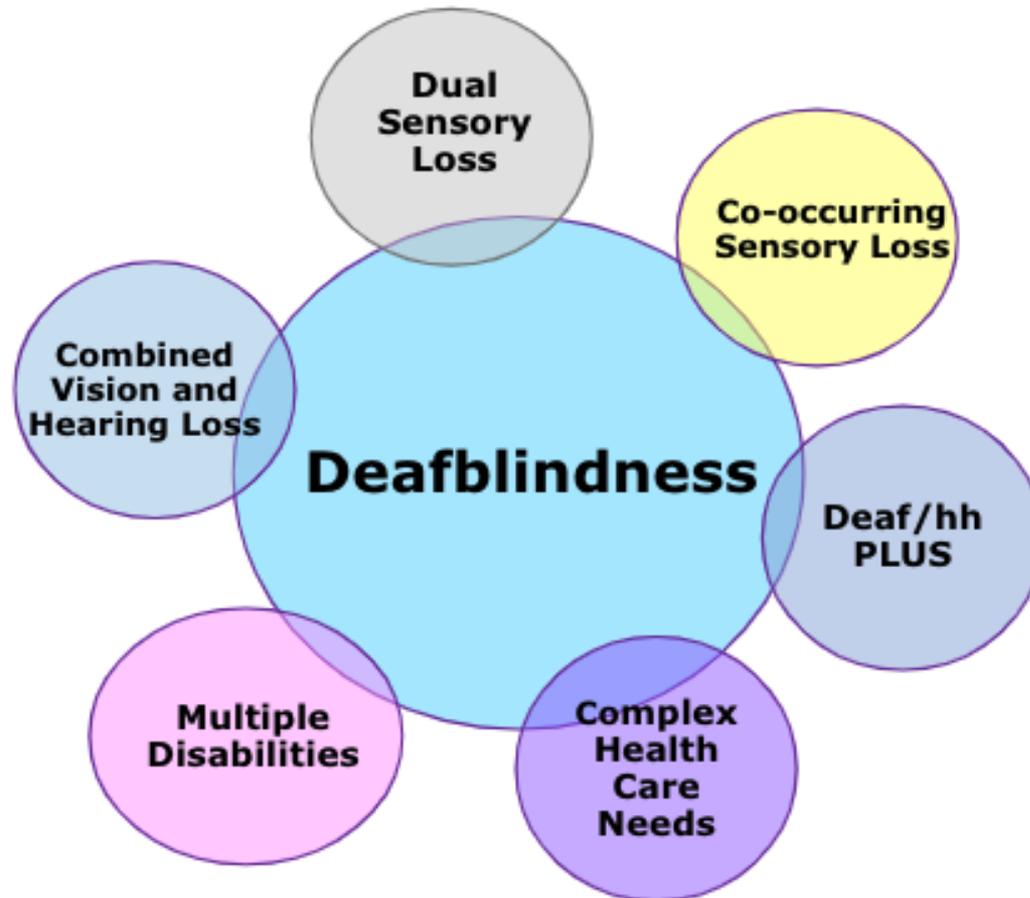
# Overview of Deaf -Blindness (2 of 2)

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- Any combined hearing and vision loss that significantly limits the child's ability to get information from people and objects around them.
- Losses can cause developmental delays: language, social skills, and mobility.
- Combined vision and hearing losses do not always limit the individual's learning potential.

# Terminology

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# Diversity in Deaf -Blindness

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- Some children achieve at high levels despite combined vision and hearing loss.
- Approximately 87% 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.

# Causes of Deaf -Blindness

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- There are a wide variety of causes of deafblindness
- Children might be at risk for having combined vision and hearing loss, due to:
  - Hereditary syndrome or disorder
  - Postnatal complications
  - Family history or genetics
  - Head Injury
  - Trauma to ear or eye
  - Infection
  - Prenatal complications

# Common Etiologies & Risk Factors

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- CHARGE syndrome
- Complications of Prematurity
- Cornelia de Lange
- Congenital Rubella
- Down Syndrome
- Meningitis
- Trisomy 13 or 18
- Usher Syndrome
- Peroxisomal Disorders
- Chronic Ear Infections
- Cortical or Cerebral Visual Impairment
- Tumors
- Congenital Cytomegalovirus (cCMV)
- Anoxia/lack of oxygen

# 2019 Child Count Data

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- Each state conducts a census of children and youth who are deafblind (birth through age 21).
- Information from all states is compiled and reported in the annual report.
- [2019 National Deaf-Blind Child Count Report](#)
- [National Deaf-Blind Child Count Interactive Maps](#)

# National Child Count

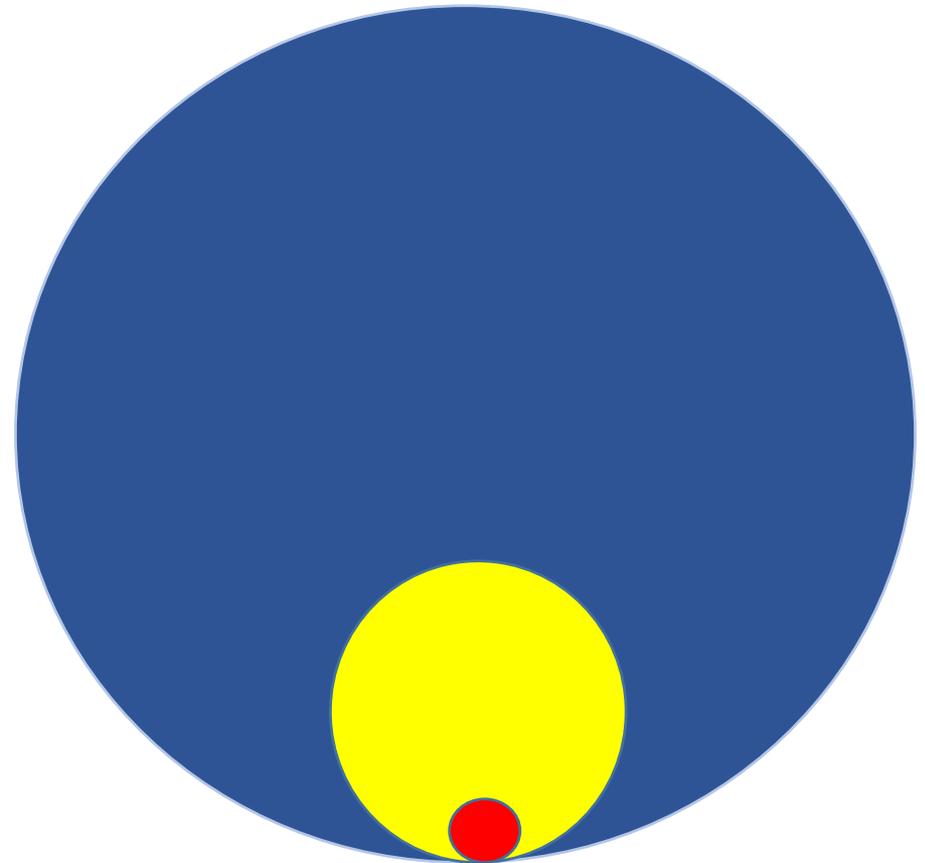
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- Overview of annual National Child Count
  - Conducted each year since 1986 to supplement Office of Special Education Programs' Federal IDEA Part B & Part C child counts
  - The National Center on Deaf-Blindness (NCDB) aggregates data from all 48 deaf-blind projects serving U.S. states and territories to identify needs and trends
  - Approximately 87% of individuals who are currently identified with deaf-blindness have additional and multiple disabilities
  - December 1, 2019 Snapshot Data: 10,627

# Low Incidence Population

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- Blue circle: All children Birth-21 in the U.S. (~90,426,142)
- Yellow circle: Children Birth-21 receiving special education (7,539,553)
- Red circle: Children age Birth-21 with deafblindness (9,904)

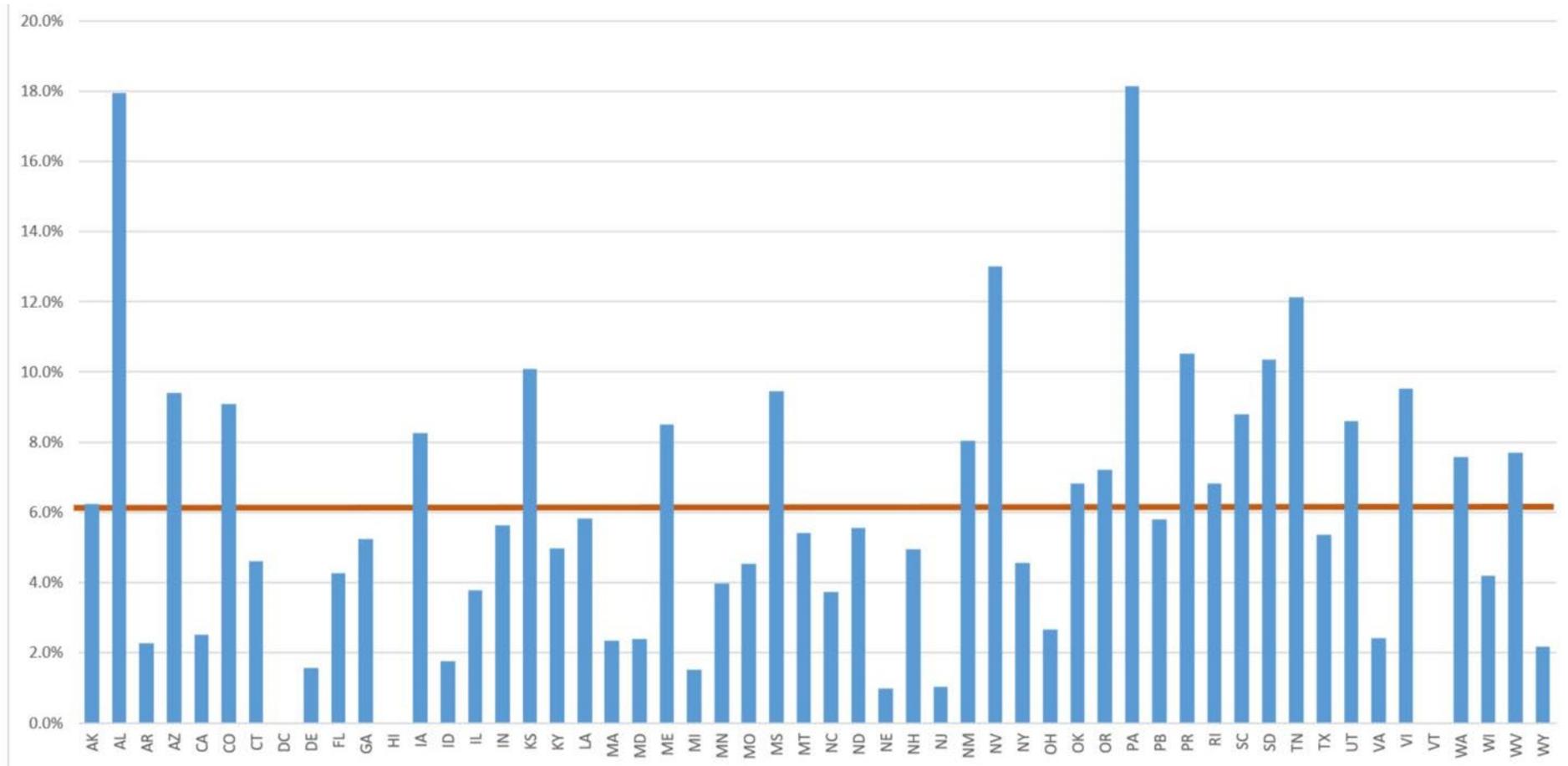


# National Child Count: Birth

# - 2

Birth - Age 2		
Age	N	% of National Total
0	72	0.7%
1	206	1.9%
2	380	3.6%
Total	658	6.2%

# National Count: Percent Birth to 2\*

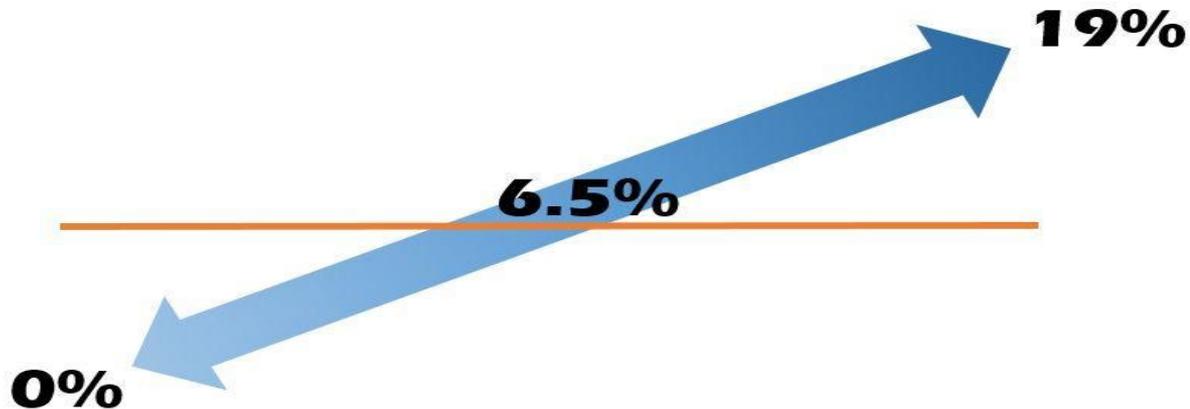


2019 National Child  
Count, NCDB

# Under Identification (1 of 3)

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Age 0-2 is 6.5% of total Deaf-Blind  
Range is 0% to 19%



# Under Identification (2 of 3)

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- Why we know that there is an under identification problem- no good prevalence data for DB
  - Range of prevalence data from state to state
  - Anecdotal from state technical assistance

# Under Identification (3 of 3)

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- The under-identification of children with deaf-blindness urgently requires partnership and collaborative actions
- Children with unidentified combined vision and hearing loss can lack access to key strategies for communication, learning, and development

# Importance of Referral

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- When both vision and hearing are affected, natural opportunities to learn and communicate can be limited.
- Children with deaf-blindness require unique skills to help access their environment.
- Connecting to services early helps young children learn how to access residual vision and hearing which fosters learning, communication, and social emotional development.

# Impact of Deaf -Blindness (1 of 3)

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- Impact Varies Based On:
  - Compounding Effects
  - Age of Onset
  - Degree of Vision & Hearing Loss
  - Additional Disabilities
  - Age of Identification

# Impact of Deaf -Blindness (2 of 3)

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- Specialized interventions matter for children and youth who are deaf-blind
- Without access all aspects of learning, connection, & development are deeply impacted

# Impact of Deaf -Blindness (3 of 3)

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- Deaf-Blindness is often referred to as a disability of access.
- Combined vision and hearing loss impacts:
  - Communication
  - Motor Skills (Gross & Fine)
    - Exploration < Mobility < Engagement < Participation
  - Social Emotional
    - Relationships < Social Interaction < Friendships
  - Visual and Mental Memory < Concept Development
  - Independence
  - Incidental Learning

# Strategies to Address Undercount

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- Analyze factors that may impact state identification rates
- Increase knowledge of risk factors and etiologies
- Form partnerships for opportunities for cross referral
- Develop partnerships to make referral systems inclusive of DB

# Take Away Questions...

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- Do the projects you work for collect data or provide services that could aid in supporting the identification and referral of children with deaf-blindness?
- Are there opportunities to improve the identification and referral of infants and toddlers who are deaf-blind within your programs?
- Are there ways that state deaf-blind projects can assist you in your work with children who are deaf-blind?

# Resources

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- [NCDB](#)
  - [State DB Project Links](#)
  - [National Child Count State Info](#)
  - [For Families](#)
- [State EHDI Information](#)
- [Hands & Voices](#)
- [Risk Factors for Combined Vision and Hearing Loss](#)
- [Sooner the Better: A Framework for Training Early Intervention Practitioners](#)

# Thank you!

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# National Center on Deaf-Blindness



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