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

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Purpose

- Participants will:

  - Increase knowledge of the under identification of infants and toddlers through observing and discussing the national deafblind child count data

  - Learn what collaborative relationships exist across the US between EHDI, Hands & Voices, and state deafblind projects

  - Identify what activities and efforts could be pursued in their states to improve identification of deafblind infants and referral to state deafblind projects
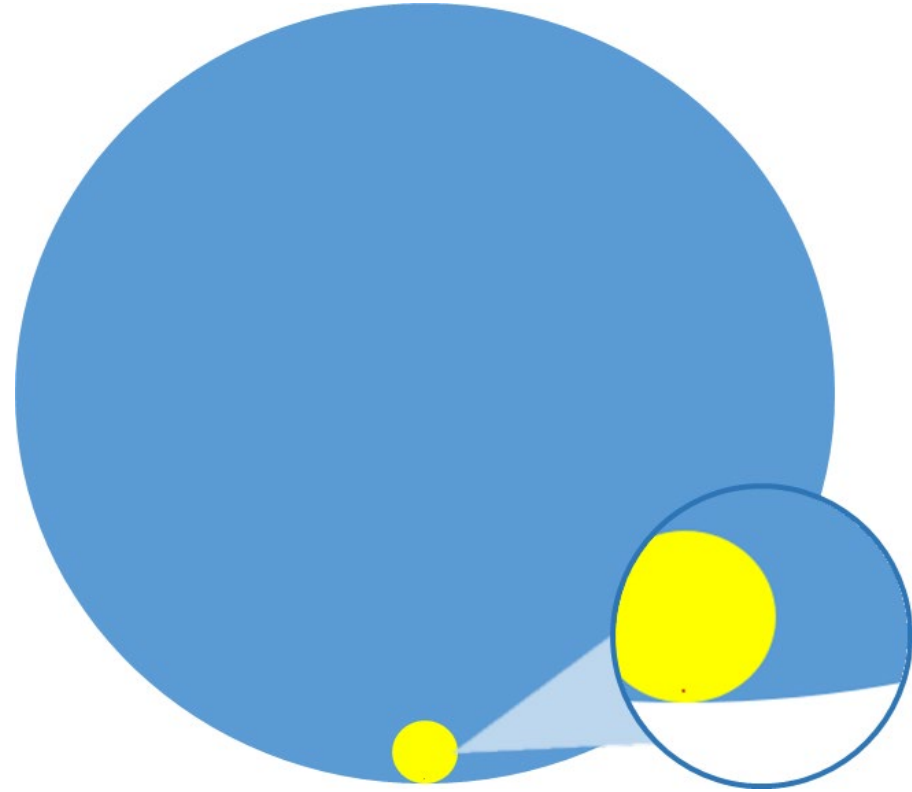
Overview of Deafblindness

What is the Child Count?

- Began in 1986: [2023 National Child Count of Children and Youth who are Deafblind](#)

- Provides information on the population of children identified as deafblind in the U.S., ages birth through 21

- Data includes state and national information on:

  - Population demographics (age, race/ethnicity/gender), type and severity of vision and hearing loss, causes of deafblindness, presence of additional disabilities, educational setting, living setting

Low Incidence Population

Children Birth - 2

- Blue circle: All infants & toddlers in the U.S. (11,034,857*)

- Yellow circle: Infants & toddlers in special education (883,030**)

- Red circle: Children with deaf-blindness (697**)

.08% of special education

National DB Count: Birth to 2 Documented Vision Loss

Documented Functional Vision Loss	**172 (28%)**
Low Vision	**166 (27%)**
Further Testing Needed	**129 (21%)**
All Other Categories	**145 (24%)**

National DB Count: Birth to 2 Documented Hearing Loss

Moderate Loss (41-55 dB loss)	**110 (18%)**
Further Testing Needed	**104 (17%)**
Profound (91+ dB loss)	**100 (16%)**
All Other Categories	**298 (49%)**

National Child Count: Birth - 2 Cortical Visual Impairment (CVI)

Age	CVI Total	Percentage of Children with CVI
0	12	0.36%
1	63	1.87%
2	110	3.26%
3	139	4.12%
4	147	4.35%
5	173	5.13%
6	204	6.02%

Top Etiologies Associated with Deafblindness

Age	Top Etiologies
0	1. CHARGE Syndrome 2. Other: Hereditary Syndromes/Disorders 3. Pierre-Robin Syndrome
1	1. Other: Hereditary Syndromes/Disorders 2. CHARGE Syndrome 3. Other: Pre-Natal/Congenital Complications
2	1. Other: Hereditary Syndromes/Disorders 2. CHARGE Syndrome 3. Other: Pre-Natal/Congenital Complications
3	1. Other: Hereditary Syndromes/Disorders 2. CHARGE Syndrome 3. Complication of Prematurity

Potential Issues Around Identification

- 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
- The pandemic- numbers are beginning to finally stabilize

It Takes a Village!

- 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!

Innovative Partnerships & Solutions

- Data Sharing Memorandums of Understanding
- Partnership Agreements
- Networking and Collaboration Activities
- Work Groups
- Part C & EHDI Data Sharing Agreements & Resource Documents

Helpful Next Steps

- Check out your state's data: National Deafblind Child Count

- 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 efricke@helenkeller.org

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