

# **Using the Deaf-Blind Child Count to Improve Identification**

**Emma Nelson, National Center on Deaf-Blindness**

# Objectives

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- Participants will...
  - Build awareness of under identification of infants and toddlers who are deaf-blind
  - Identify potential opportunities to increase identification and referral through partnerships

# National Center on Deaf-Blindness

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- Technical Assistance and Dissemination Center
- Goal is to improve services, educational results, and quality of life for children who are deaf-blind
- Works closely with state deaf-blind projects and other partners across the country
- Maintains the National Deaf-Blind Child Count

# Overview of Deaf-Blindness

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- “Deaf-Blindness” refers to any range of combined vision and hearing loss that significantly limits the child’s ability to get information from people, objects, and activities around them
- Losses can cause developmental delays: language/communication, social emotional skills, cognition, adaptive, and motor
- Correctly identifying a student as deaf-blind creates the potential to develop a more appropriate IFSP or IEP and deliver more effective services
- Identification and referral of children with deaf-blindness requires partnership and collaborative actions

# Benefits of Early ID and Referral

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- **SUPPORT:** Technical Assistance (TA) and support to families and providers as early as possible to improve child outcomes
- **COMMUNITY:** Connect families to a community of families who understand their unique experiences and support needs
- **UNDERSTANDING:** Help educators and researchers understand the developmental and educational needs of children with dual sensory loss
- **HOW MANY:** Combined data can be used to improve local, state, and federal policies and practices for children with dual sensory losses

# National Deaf-Blind Child Count

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- Conducted annually
- Supplement OSEP's Federal IDEA Part C and Part B child counts
  - Part B: Includes children as deaf-blind only when deaf-blindness is their single disability
- Deaf-Blind Child Count
  - Data on children whose disability category is deaf-blind AND those identified with deaf-blindness and have additional disabilities
- 87% of children on the National Deaf-Blind Child Count have one or more disabilities in addition to deaf-blindness

**Source:** [2019 National Deaf-Blind Child Count](https://www.nationaldb.org/products/national-child-count/report-2019/);

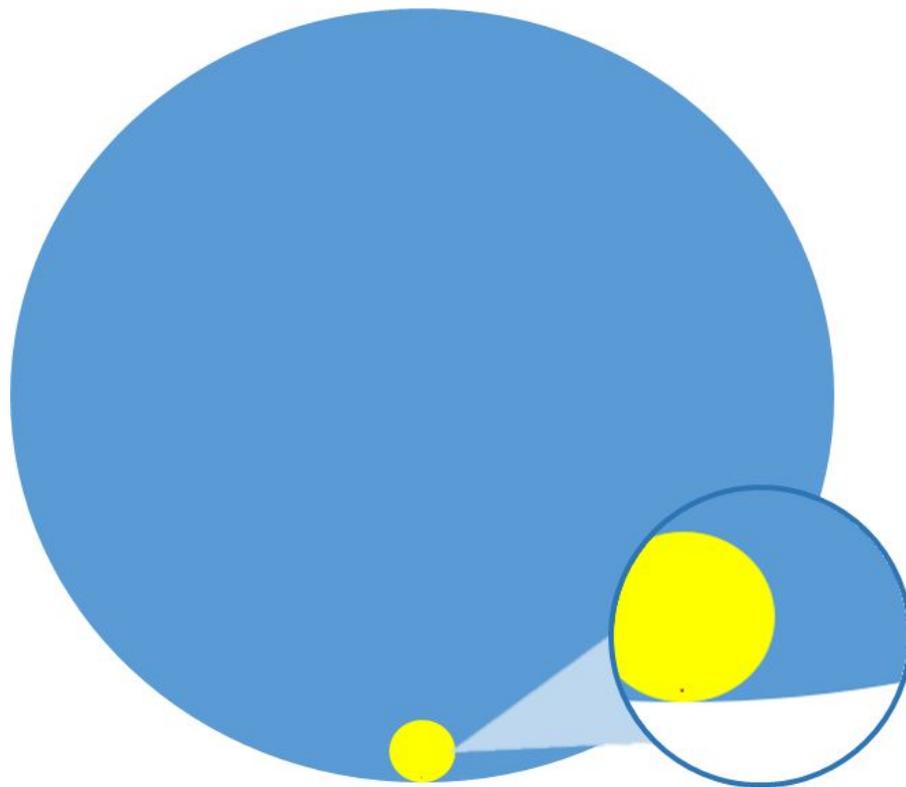
<https://www.nationaldb.org/products/national-child-count/report-2019/>

# Low Incidence Population

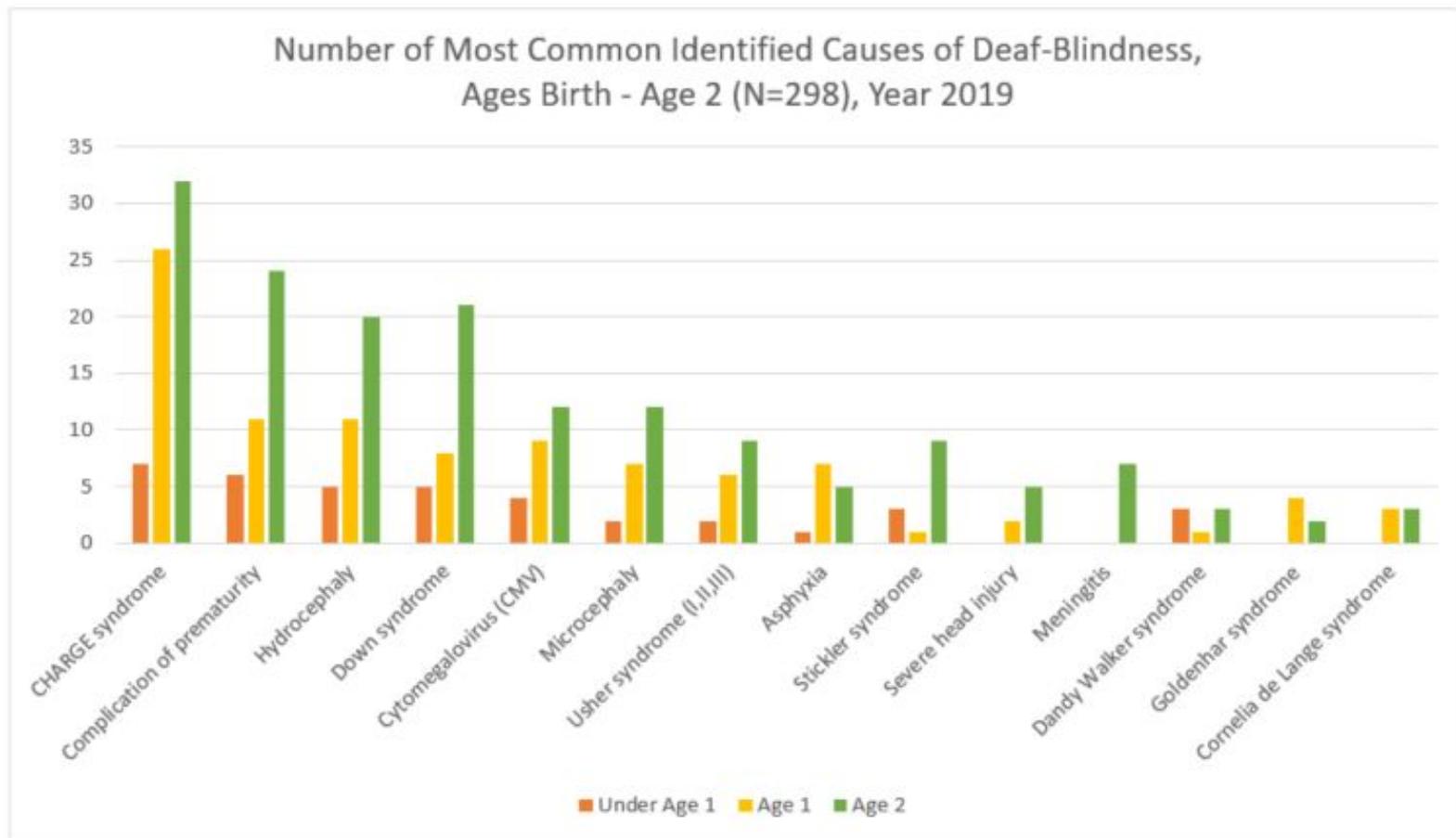
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## Children Birth - 21

- Blue circle: All children in the U.S. (~90 mil\*)
- Yellow circle: Children in special education (7,585,335\*) 8% of U.S.
- Red circle: Children with deaf-blindness (10,525^)  
.16% of special education

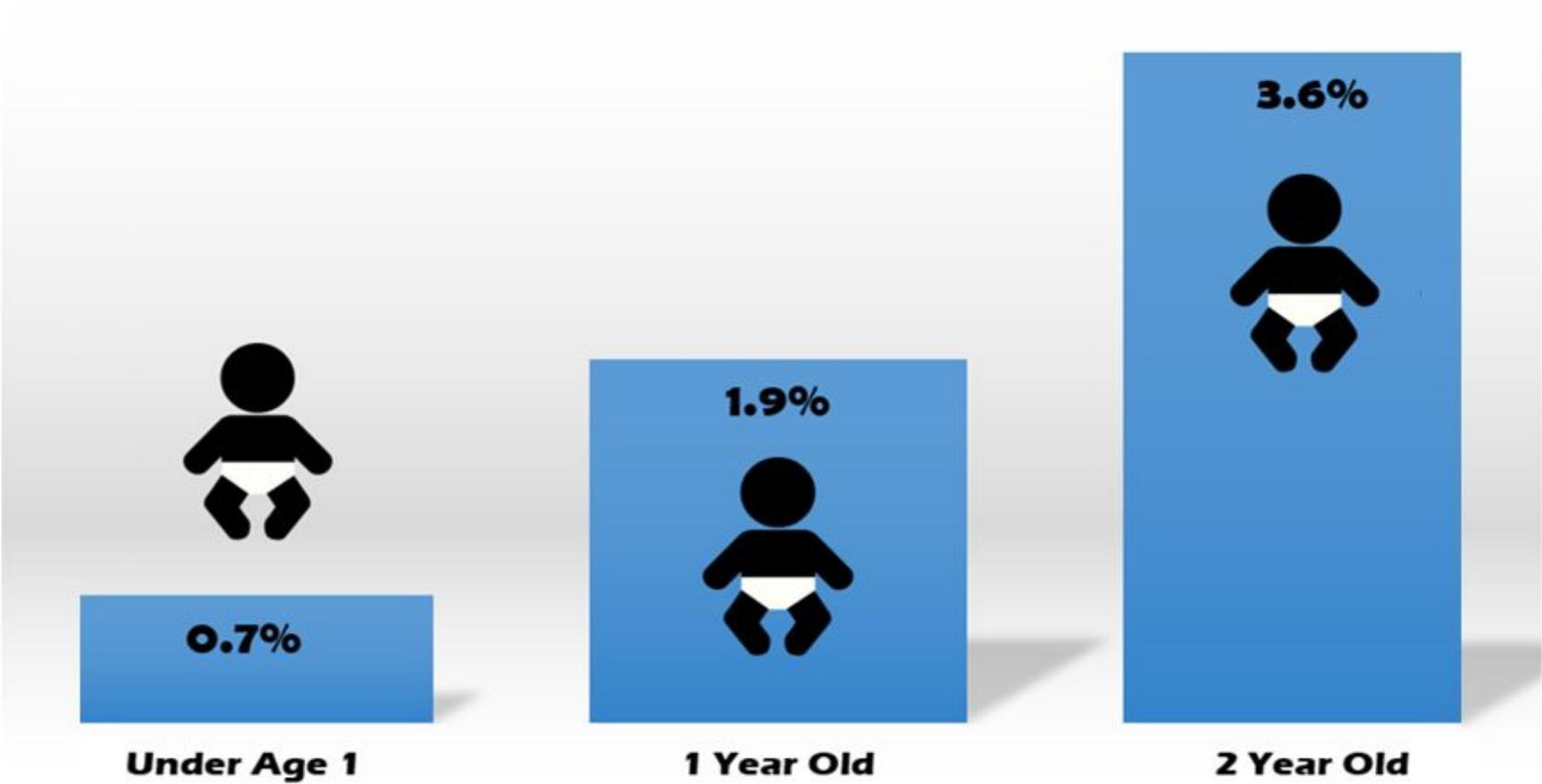


# Most Common Causes

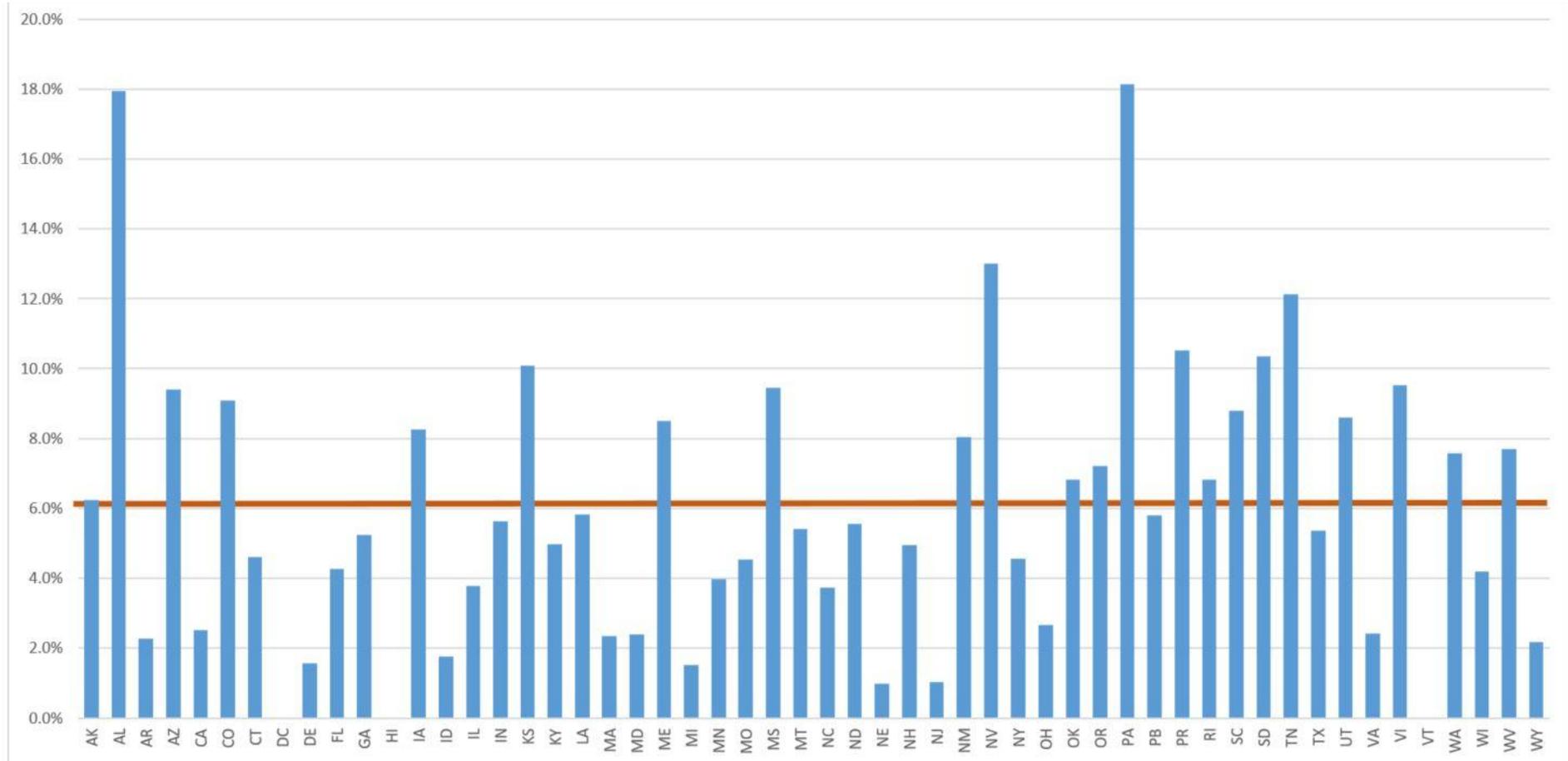


Source: 2019 National Deaf-Blind Child Count

# Deaf-Blind 0-2 Population



# National DB Count: Percent Birth to 2

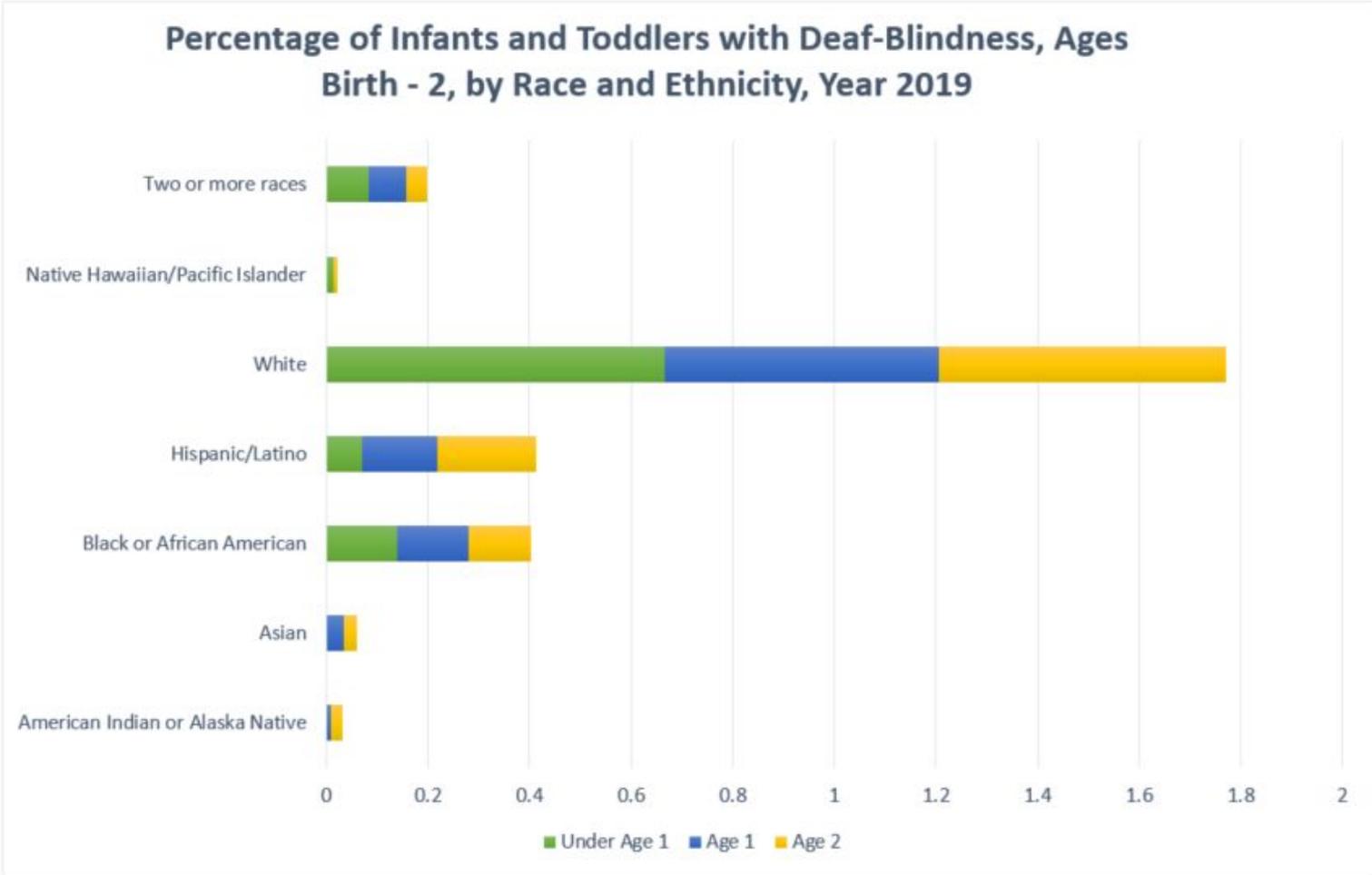


2019 National Child Count, NCDB

# National DB Child Count: Birth - 6

Age	N	% DB Total
Under 1	72	0.7%
1	206	1.9%
2	380	3.6%
3	431	4.1%
4	435	4.1%
5	433	4.1%
6	495	4.7%

# Race and Ethnicity



Source: 2019 National Deaf-Blind Child Count, NCDB

# Emerging Research in Subset Populations: Usher syndrome

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- Partnership with Usher syndrome Coalition
- Large shift in identifying children with Usher syndrome at a young age due to genetic testing
- State Example: Arizona
  - There has been a large increase in infants diagnosed with the Usher gene before age 1 due to genetic testing
  - In one year (April 2021 - October 2021)
    - 7 individuals referred to the project, 6/7 of had Usher.
    - 5 were under 5

# TA Center Partnership Activities

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- Build on common core values:
  - Improving child and family outcomes
  - Diversity and equity means serving ALL children
- Strengthening systems through collaboration
- Using data to drive improvement
- Collaboration activities
  - Co-hosting webinars
  - Disseminating information
  - Linking to resources
  - Co-writing articles and briefs



# Additional Partnerships: Family Organizations

- Hands & Voices



- National Foundation for Deaf Blind (NFADB)



- CHARGE Syndrome Foundation



- Usher Syndrome Coalition



- Center for Parent Information & Resources



# How Can We Partner?

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- What collaborative relationships should be pursued to improve identification?
- What types of data would be helpful to improve identification?
- What activities and efforts should be pursued to improve identification?



# National Center on Deaf-Blindness



**Emma Nelson, Identification & Referral Lead**  
**[emma.nelson@hknc.org](mailto:emma.nelson@hknc.org)**

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