



Identification and Referral of Children with Deaf-Blindness

Experiences that occur during the earliest years of life have a profound effect on a child's ability to learn, move, and interact with others. This is especially true for children with combined vision and hearing loss—known as deaf-blindness—whose physical, communication, cognitive, social, and emotional developmental domains are deeply intertwined. Because the impact on learning is exponentially greater for combined vision and hearing loss than for vision or hearing loss alone, early intervention services from individuals who understand the unique impact of deaf-blindness is essential.

Part C providers play a critical role in the identification and referral of children who are deaf-blind, and a network of technical assistance projects consisting of the National Center on Deaf-Blindness (NCDB) and state deaf-blind projects (SDBPs) is here to help. The network provides opportunities for inter-agency collaboration through training and technical assistance designed to increase the capacity of national, state, and local service providers; systems; and agencies to identify children (ages birth through 21) who are deaf-blind and refer them to their state projects as early as possible, ideally during infancy. Once children are identified, their families can be linked to appropriate services and support. To learn more about NCDB's Child Find efforts, visit the [Identification and Referral](#) page of the [NCDB website](#).

Although the term deaf-blind might seem to imply a complete absence of hearing and sight, it actually refers to varying degrees of vision and hearing loss. If you know or suspect you have an infant or toddler with deaf-blindness on your caseload, contact your SDBP for information about support, training, and consultation. Contact information can be found on the NCDB website at nationaldb.org.

Below, you will find information about deaf-blindness, the importance of identification and referral of infants and toddlers with combined vision and hearing loss, and resources and training opportunities.

WHAT IS DEAF-BLINDNESS?

- Combined vision and hearing loss, also known as deaf-blindness, is a rare condition that limits access to both auditory and visual information.
- According to the [2019 National Deaf-Blind Child Count](#), there are 10,627 children, birth to age 21, in the U.S. who have been identified as deaf-blind, including 658 infants and toddlers.
- Deaf-blindness is the lowest incidence disability, and within this population there is great variability in terms of age, race/ethnicity, cause of deaf-blindness, and severity and type of hearing and vision loss.
- 87% of children who are deaf-blind have additional communication, physical, medical, and/or cognitive disabilities.
- Having multiple disabilities or complex health care needs often keeps deaf-blindness from being identified in infants and toddlers, therefore limiting access to appropriate interventions.

IMPORTANCE OF REFERRAL TO A STATE DEAF-BLIND PROJECT

If you are a provider who works with a family that has a child with deaf-blindness and have not yet contacted your SDBP, please do so as soon as possible. The types of services offered vary from state to state but typically include resources, guidance, connection to other families, and annual workshops or other events. Most state projects have a family engagement coordinator on staff who works directly with families. See the [State Deaf-Blind Projects page](#) on the NCDB website for contact information.

IMPORTANCE OF IDENTIFICATION

If you suspect that a child you work with has combined vision and hearing loss, having them evaluated will help determine if the child qualifies for additional services and support. SDBPs can help early intervention providers, educators, related service providers, and families gain knowledge and skills to provide effective intervention. Identification as early as possible is important for many reasons, including the following:

- When both vision and hearing are affected, natural opportunities to learn, build relationships, and communicate can be limited.
- Intervention techniques and methods for children with deaf-blindness are different than those for children who have vision or hearing loss alone.
- Children with deaf-blindness require unique skills to access their environments.
- Starting early helps young children with deaf-blindness learn to use any residual vision and hearing they have to maximize their ability to build social relationships and communication and language skills.

RESOURCES & TRAINING

Family Resources

Resources that you can refer families to for information and support

- [For Families Section](#) of the NCDB website
- [National Family Association for Deaf-Blind](#)

Professional Development

Training materials to embed into professional development for early intervention and 619 providers

- [The Sooner the Better: A Framework for Training Early Intervention Practitioners on Deaf-Blindness](#)
- [Online Professional Development Course: Deaf-Blindness for Early Intervention Practitioners](#)

National Center on Deaf-Blindness, February 2021

nationaldb.org

The contents of this publication were developed under a grant from the U.S. Department of Education, #H326T180026. However, those contents do not necessarily represent the policy of the U.S. Department of Education, and you should not assume endorsement by the Federal Government. Project Officer, Susan Weigert.

