

IDENTIFICATION OF CHILDREN WITH DEAF-BLINDNESS: RESOURCES FOR SCHOOL ADMINISTRATORS

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**National Center
on Deaf-Blindness**

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OVERVIEW

This article provides information and resources to help school administrators increase their knowledge of deaf-blindness and how they can support identification of students who are deaf-blind. It includes information about deaf-blindness, a rare condition that limits access to both auditory and visual information; details about two national child counts—the IDEA Part B federal count and the National Deaf-Blind Child Count; and information and strategies administrators can use to ensure that children with deaf-blindness are identified, referred, and receive appropriate services.

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**National Center
on Deaf-Blindness**



Office of Special Education Programs
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Children and Youth with Deaf-Blindness

Experiences that occur during a child’s school years have a profound effect on their ability to learn, develop social relationships, and prepare for adult life. This is especially true for children and youth with combined vision and hearing loss—known as deaf-blindness—whose physical, communication, cognitive, social, and emotional developmental domains are deeply intertwined.

Although the term deaf-blind might seem to imply a complete absence of hearing and sight, it refers to varying degrees of vision and hearing loss.

In general, deaf-blindness involves a combination of hearing and vision loss where those senses are reduced, distorted, or missing entirely. Because the impact on learning is exponentially greater for combined vision and hearing loss than for vision or hearing loss alone, special education and related services from individuals who understand the unique impact of deaf-blindness are essential.

Deaf-Blindness Defined

- Combined vision and hearing loss, or 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, ages birth through 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, cause of deaf-blindness, and severity and type of hearing and vision loss.
- The range and types of hearing and vision loss are evidence of the heterogeneous nature of the population of children with deaf-blindness. Only about 1% have both profound hearing loss and total blindness, while 99% have some usable hearing or vision.
- Approximately 85% of children who are deaf-blind have additional communication, physical, medical, and/or cognitive disabilities.
- Having multiple disabilities or complex healthcare needs often keeps deaf-blindness from being identified in children, a situation that limits their access to appropriate interventions.
- The complexity of needs associated with this disability requires continued evolution and adaptation of local, state, and national services and supports.



Administrators Support of the Identification Process

The role of school administrators is critical in supporting the identification and referral of children who are deaf-blind to ensure they receive a free appropriate education including special education and related services.



Key strategies for administrators to consider include

- Advocating for improved policy at local, state, and federal levels regarding identification, referral, and data collection to meet the needs of children and youth who are deaf-blind, their families, and the professionals who support them
- Ensuring the identification process is conducted in accordance with the Individuals with Disabilities Education Act (IDEA) requirements, which include early and accurate identification, even when multiple disabilities are present
- Referring children and youth who are deaf-blind and their families to the state's deaf-blind project
- Accessing information and resources from the National Center on Deaf-Blindness (NCDB) and state deaf-blind projects
- Ensuring key personnel in the school system are trained and have experience working with children and youth with deaf-blindness and their families
- Ensuring families and healthcare providers are part of the identification process
- Intentionally collaborating across agencies, including education, health, and social services, to share information and resources that support high quality identification processes
- Ensuring enough qualified personnel and fiscal resources are available to identify children and youth who are deaf-blind
- Ensuring there are no fiscal incentives to identify children who are deaf-blind in categories other than "deaf-blindness"

Key Components of the Identification Process

IDEA requires the following key components as part of the identification process:

- **Child Find:** Local education agencies (LEAs) have the responsibility of designing a process to inform the public and to identify, locate, and evaluate children, including those suspected of deaf-blindness, ages 3 through 21, who may be eligible for special education and related services. Likewise, children and youth suspected of having a disability, including those who may be deaf-blind, are referred for an evaluation.
- **Evaluation:** A multidisciplinary team of qualified professionals, including those with expertise in vision, hearing, and deaf-blindness, completes the evaluation, which must be conducted in the family's native language and include formal and informal measures from multiple sources in the following domains: cognitive, physical, communication, social/emotional, functional, developmental, and educational.
- **Eligibility:** An eligible child or youth is age 3 through 21 and, due to one or more of the following conditions, is unable to receive reasonable educational benefit from regular education: intellectual disability, hearing impairment (including deafness), speech or language impairment, visual impairment (including blindness), serious emotional disturbance, orthopedic impairment, autism, traumatic brain injury, other health impairment, specific learning disability, deaf-blindness, multiple disabilities, and developmental delay (children age 3 through 9).
- **Data Reporting:** LEAs and state education agencies (SEAs) must submit data about children with disabilities (3 through 21 years of age) who receive special education and related services. Data collections authorized under IDEA Part B include child counts according to the primary disability category, educational environments, personnel, exiting, discipline, assessment, dispute resolution, and maintenance of effort reduction and coordinated early intervening services.



Counting and Reporting Children Who Are Deaf-Blind

There are two national child counts for children and youth who are deaf-blind:

- The IDEA Part B federal count is conducted annually by LEAs and SEAs and reported to the Office of Special Education Programs (OSEP) at the U.S. Department of Education. This child count only includes children for whom deaf-blindness is their single disability. Many children who are deaf-blind and have additional disabilities are identified and reported in the IDEA disability category “multiple disabilities.”
- The National Deaf-Blind Child Count is conducted each year. This count is made to meet federal grant requirements for both the state and multi-state deaf-blind technical assistance projects and NCDB as well as to serve as a common data collection and reporting mechanism for use nationwide. The National Deaf-Blind Child Count helps identify national and state technical assistance needs for children and youth who are deaf-blind, their families, and the service providers and systems that serve them. In contrast to OSEP’s Part B child count, National Deaf-Blind Child Count data are collected for children whose disability is solely deaf-blindness as well as those who are identified with deaf-blindness and have additional disabilities.

Differences in the Two Deaf-Blind Child Counts

The 2019 IDEA Part B federal count reported that only 1,606 children and youth ages 3 through 21 had deaf-blindness.

In contrast, the 2019 National Deaf-Blind Child Count reported that 9,867 children and youth ages 3 through 21 were eligible to receive services from state deaf-blind projects and were being served through IDEA Part B. Approximately 85% of the children and youth on the National Deaf-Blind Child Count had one or more additional disabilities. Consequently, most children and youth who are deaf-blind are not identified as such on the IDEA Part B federal child count.

This discrepancy is due to an IDEA federal regulation, described to the left, that only allows children for whom deaf-blindness is their single disability to be reported on the IDEA Part B child count. Many experts and advocates would like to see the IDEA federal regulation amended to reflect a count similar to the National Deaf-Blind Child Count, which is much more inclusive and reflective of the actual number of children and youth who are deaf-blind.



Outcomes of the Child Count Discrepancies

The discrepancy between OSEP’s IDEA Part B child count and the National Deaf-Blind Child Count is significant. In their data submitted for the IDEA child count, state deaf-blind projects consistently demonstrate that most SEAs report students who are deaf-blind using the disability category “multiple disabilities” instead of deaf-blindness.

Concerns about the under-identification of deaf-blindness have been a consistent problem because not identifying a child as deaf-blind can result in a lack of or delay in receiving appropriate intervention and instruction critical to a child’s early development and learning (Herbster, 2015; Müller, 2006; Purvis & Schalock, 2014).

Assessment and instructional strategies used for children and youth with deaf-blindness are quite different from those used for either hearing or vision loss.

In addition, children and youth may not be receiving special education or related services from personnel who have training and experience in deaf-blindness.

Additionally, without clear and accurate data, it is difficult to determine needed fiscal resources, pre-service and in-service development, research, educational resource development and dissemination, and policy initiatives.



Information and Resources from the National Center on Deaf-Blindness

NCDB is a national technical assistance project funded by OSEP at the U.S. Department of Education. NCDB provides technical assistance to state deaf-blind projects and other partners to improve education results and quality of life for children and youth who are deaf-blind and their families. Information and resources valuable to school administrators, their educational and health teams, and families can be found on their website at nationaldb.org.

State Deaf-Blind Project Technical Assistance

The [state deaf-blind projects](#) are funded by OSEP at the U.S. Department of Education. They provide technical assistance in all 50 states as well as Puerto Rico, the District of Columbia, the Pacific Basin, and the Virgin Islands.

State deaf-blind projects may provide the following services to improve results for children and youth who are deaf-blind and their families:

- Work closely with early intervention and education providers to address the high-intensity educational needs of children and youth who are deaf-blind and prepare them for a successful transition to adult life
- Facilitate family involvement in education and transition opportunities and connection to other families with children and youth who are deaf-blind
- Collaborate with OSEP-funded parent training and information centers
- Conduct activities to increase early identification and referral
- Promote access to and progress in the general education curriculum and grade-level academic content standards
- Provide professional development on deaf-blindness to educational teams and families
- Collaborate with NCDB, state and local education agencies, families, and other partners to conduct the annual National Deaf-Blind Child Count



Take Action: Strategies to Ensure Children and Youth Who Are Deaf-Blind are Referred and Served

- Access the NCDB website at nationaldb.org to become familiar with resources and to find your state's [deaf-blind project](#).
- Sign up for News and Events alerts on the NCDB website. Provide information to families about this valuable resource.
- Contact your state deaf-blind project to learn about available technical assistance and resources.
- Inform families of the importance and benefits of referring their child or youth to their state deaf-blind project.
- Provide information to families about [family organizations](#) that provide information and resources on deaf-blindness.
- Participate in the annual [National Deaf-Blind Child Count](#).
- Provide opportunities for all personnel to engage in pre-service and in-service training on the referral process and data reporting.
- Access the Council for Exceptional Children's standards for [interveners](#) and [teachers](#).

Serving children who are deaf-blind involves a shared commitment and understanding of the complexity of deaf-blindness to help ensure their needs and those of their families are met. Early identification and referral are the key to high quality programs, services, supports, and outcomes. As such, school administrators play a key role in leading teams to ensure every child and youth who is deaf-blind receives a free appropriate education.

REFERENCES

Herbster, H. (2015). *Special education eligibility and the category of deaf-blindness: Examining the perspectives of case coordinators*. [Doctoral Dissertation]. Ohio State University.

Müller, E. (2006). *Deaf-blind child counts: Issues and challenges*. *inForum (Brief Policy Analysis)*. Project Forum at NASDE.

National Center on Deaf-Blindness. (2020). *The 2019 national deaf-blind child count report*.

Purvis, B., & Schalock, M. D. (2014). Using evidence-based strategies and technical assistance to improve identification of infants and toddlers with combined vision and hearing loss. *Visual Impairment and Deafblind Education Quarterly*, 59(5), 20-24.

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