



Comprehensive Definition of Deaf-Blind

Our Mission: NFADB exists to empower the voices of families with individuals who are Deaf-Blind and advocate for their unique needs.

What we believe: NFADB believes individuals who are Deaf-Blind are valued members of their communities and should have the same opportunities and choices as others in the community.

Our Position: Deaf-Blind organizations; family organizations; policy makers and decision makers, including representatives of state and federal agencies; and other stakeholders should come together to develop a comprehensive definition of Deaf-Blind that ensures that individuals who are Deaf-Blind of all ages receive high-quality services that meet their needs throughout their lives.

Where We Are Now: Currently, there is no comprehensive, universally adopted definition of Deaf-Blind. Definitions that do exist do not always acknowledge that there is a wide range of severity of vision and hearing loss or apply to all individuals who are deaf-blind, such as those who will become deaf-blind due to progressive vision or hearing loss and those who have additional disabilities. This results in

- Underidentification
- Ineligibility for services for individuals who do not meet the definition used by a particular agency or program
- Individuals with milder forms of vision and/or hearing loss not being identified as Deaf-Blind
- Confusion on the part of service providers about what being Deaf-Blind means
- Insufficient services and funding for services due to a lack of universal recognition of what it means to be Deaf-Blind

One specific current problem for children relates to the following requirement in the Individuals with Disabilities Education Act regulations that describes how state education agencies should count children who are deaf-blind for an annual report to Congress.

(1) If a child has only two disabilities and those disabilities are deafness and blindness, and the child is not reported as having a developmental delay, that child must be reported under the category “deaf-blindness.”

(2) A child who has more than one disability and is not reported as having deaf-blindness or as having a developmental delay must be reported under the category “multiple disabilities.”

(Individuals with Disabilities Education Act, 2006, p. 46804)

Because the majority of children who are deaf-blind have additional disabilities, this results in significant undercounting of children who are deaf-blind.

Consequences:

- Our family members who are Deaf-Blind may not be identified as Deaf-Blind or not meet the definition used by a specific agency or program, and thus fall through the cracks and not receive the services they need.
- Services are delayed for our family members who are Deaf-Blind due to a lack of timely identification.
- Because not all individuals who are Deaf-Blind are identified, the overall population size is underestimated and the full need for services and qualified personnel is not recognized.
- Appropriate services and personnel are not available for our family members who are Deaf-Blind due to a lack of understanding of the needs of the population.
- As a result of delayed or missed identification, our children who are Deaf-Blind are more likely to miss crucial incidental learning and have delayed learning and delayed development of social/emotional skills and well-being.
- Lack of a clear, universal definition contributes to a misunderstanding about what deaf-blindness is by education, healthcare, and rehabilitation providers as well as their roles and responsibilities when working with our family members who are Deaf-Blind.

Where We Should Be: A universal, comprehensive definition that would follow individuals who are Deaf-Blind throughout their lives would clarify confusion about what being Deaf-Blind means and lead to the benefits listed below. The definition should include all etiologies of deaf-blindness and all age groups and address the following important points:

- Being Deaf-Blind is a unique condition.
- The multiplicative effects of combined vision and hearing loss result in ways of learning and experiencing and interacting with the world that are different from either vision or hearing loss alone.
- Being Deaf-Blind involves combined vision and hearing loss to the extent that neither of these senses can compensate for the lack of the other.

- Being Deaf-Blind creates an inability to access both visual and auditory information about people and things in the environment necessary for learning, communication, and overall development.
- Being Deaf-Blind can be a socially isolating condition.

The definition should also reflect that people who are Deaf-Blind can meet high expectations and be successful in all areas of their lives when this unique condition is understood and appropriate services and accommodations are provided.

Benefits of a Universal Definition:

- Our family members who are Deaf-Blind would receive the services they need throughout their lives.
- There would be better communication among agencies serving our family members who are Deaf-Blind because personnel would understand what it means to be Deaf-Blind and the importance of appropriate services.
- Understanding of the needs of our family members who are Deaf-Blind and their needs would increase and that recognition would lead to more funding for and the availability of high-quality services.
- Our children who are Deaf-Blind would receive services early in life. As a result, their ability to learn will increase and they will have a chance to become productive members of society.
- Our families' happiness and quality of life would increase because we would have more support in caring for our family members who are Deaf-Blind.

Reference:

Department of Education. (2006). 34 CFR Parts 300 and 301: Assistance to States for the Education of Children With Disabilities and Preschool Grants for Children With Disabilities; Final Rule. *Federal Register*, 71(156), 46540-46845.

<https://sites.ed.gov/idea/files/finalregulations.pdf>

Resources:

[IDEA Definition](#)

[Cogswell-Macy Act](#)

[We Count Too! Why Define Deaf-Blind?](#)

[Identifying Dual Sensory Loss in Students With the Most Significant Cognitive Disabilities](#)