AN OVERVIEW OF DEAFBLINDNESS

What is deafblindness?

Deafblindness is a unique disability. It is a child who is deafblind has a combination of hearing and vision loss where these senses are reduced, distorted, or missing entirely.

Most children who are deafblind have some usable vision and/or hearing. Some are profoundly deaf and totally blind.

Deafblindness varies from person to person based on things like the cause, level of hearing and vision loss, and additional disabilities.

Although no two children who are deafblind are alike, many are similar needs. They may need help from others to understand their world, communicate, and build social relationships.

What causes deafblindness?

Children who are deafblind make up one of the most diverse and complex of all disability groups. More than 70 causes have been identified for deafblindness.

- 10% - Complications from Prematurity
- 47% - Hereditary Syndromes/Disorders (e.g., Usher syndrome, CHARGE syndrome)
- 14% - Prenatal Complications (e.g., cytomegalovirus, hydrocephaly)
- 12% - Postnatal Complications (e.g., meningitis, severe head injury)
- 17% - Etiology Undetermined

Some causes are so rare that only a few children have been identified with them. Sometimes there’s no known cause.

Of children with deafblindness...

- 50% have complex healthcare needs
- 85% have one or more additional disabilities
- 20% take their state’s regular grade-level assessments
- 52% take their state’s alternate assessments

Some children are born with their disability, while others lose their vision or hearing over time.

- 1% - Only about 1% of children with deafblindness have both profound hearing loss and total blindness.
- The other 99% have some usable hearing or vision.

- 4% - are totally blind
- 20% - have partial visual loss

How many children in the U.S. are deafblind?

About 10,000 children in the U.S., ages birth-21, have been identified as deafblind. Many more have not been identified, and in some, other terms might be used such as:

- Deaf plus
- Visual impairment and additional disabilities
- Multiple disabilities

How do children who are deafblind communicate?

Children who are deafblind have unique ways of interacting with others and the world around them. For many, this involves seeing through touch. Some also use sign language, and some use sign language.

Each child who is deafblind has their own special way of communicating.

How do children who are deafblind learn?

A child with combined hearing and vision loss requires thoughtful planning, individualized educational strategies, and support to reach their full potential.

Timely identification of a child who is deafblind is essential so they can begin receiving specialized services and support.

Who helps support children who are deafblind?

In addition to the family, a network of people may be part of the educational team of a child who is deafblind, such as a teacher of the deafblind, a teacher of the deaf or hard of hearing, and a teacher of students with visual impairments.

A strong relationship with a trusting adult creates a “home base” from which a child who is deafblind can grow...expanding and enriching the child’s life.

Where Can I Learn More?

State deaf-blind projects in all 50 states, including Puerto Rico, the District of Columbia, the Pacific Basin, and the Virgin Islands, provide a range of services that benefit children and their families. Visit nationaldb.org for more information and to connect with your state’s deaf-blind project.