### What is deafblindness?

- **Deafblindness is a unique disability.** A child who is deafblind has a combination of hearing and vision loss where those 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 share 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.

<table>
<thead>
<tr>
<th>Percentage</th>
<th>Cause Description and Examples</th>
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</thead>
<tbody>
<tr>
<td>10%</td>
<td>Complications from Prematurity</td>
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<tr>
<td>47%</td>
<td>Hereditary Syndromes/Disorders</td>
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<td></td>
<td>(e.g., Usher syndrome, CHARGE syndrome)</td>
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<tr>
<td>14%</td>
<td>Prenatal Complications</td>
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<tr>
<td></td>
<td>(e.g., cytomegalovirus, hydrocephaly)</td>
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<tr>
<td>12%</td>
<td>Postnatal Complications</td>
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<tr>
<td></td>
<td>(e.g., meningitis, severe head injury)</td>
</tr>
<tr>
<td>17%</td>
<td>Etiology Undetermined</td>
</tr>
</tbody>
</table>

*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.

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. But many more have not been identified. In some children, deafblindness may not be recognized and other terms might be used such as deaf plus, visual impairment and additional disabilities, or 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. Each has their own strengths. For many, this involves connecting through touch. Some children also use speech, and some use sign language.

To help children who are deafblind form connections with others and build relationships, providers, family members, and friends need to take advantage of each child’s unique strengths and abilities.

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, individualized educational strategies and support to ensure they can reach their full potential.

Deafblindness limits access to information that's needed for learning, communication, and development.

Most children who are deafblind

- Learn best when they have motivating environments tailored to their sensory abilities and other characteristics.
- Benefit from being intentionally taught concepts that typically come naturally to their hearing-sighted peers.
- Take more time to learn concepts and develop communication skills than children with typical hearing and vision.

Timely identification of a child who is deafblind is essential so they can begin receiving specialized services and support that will impact their learning.

Who helps support children who are deafblind?

In addition to the family, a number of people may be part of the educational team of a child who is deafblind:

- Teacher of the deafblind or deafblind specialist
- Intervener
- General education teacher
- Special education teacher
- Early intervention provider
- Teacher of the deaf or hard of hearing
- Teacher of students with visual impairments

- Orientation and mobility specialist
- Physical therapist
- Occupational therapist
- Speech-language pathologist
- Nurse
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.

State deaf-blind projects

State deaf-blind projects in all 50 states, including Puerto Rico, the District of Columbia, the Pacific Basin, and the Virgin Islands, provide a wide range of services for children and their families:

- Assist early intervention and education providers to address the educational needs of children who are deafblind and prepare them for a successful transition to adult life
- Facilitate family involvement in education and transition planning
- Collaborate with parent training and information centers
- Conduct activities to increase identification and referral
- Promote access to and progress in the general education curriculum and grade-level academic content standards

For more information and to connect with your state’s deaf-blind project, visit the National Center on Deaf-Blindness at nationaldb.org.