

Quarterly Newsletter

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Seeing the Whole Child: Early Identification of Deafblindness

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Imagine a toddler who seems withdrawn, slow to respond, and difficult to engage. Well-meaning adults might chalk it up to temperament or developmental variation. But for some children, what looks like quiet or inattentiveness is something far more significant: a combined loss of vision and hearing that is quietly shaping — and limiting — every interaction with the world around them.

These children have deafblindness. And the earlier we identify them, the better their outcomes can be.

What is Deafblindness?

Under IDEA (the Individuals with Disabilities Education Act), deafblindness is defined as:

“Concomitant hearing and visual impairments, the combination of which causes such severe communication and other developmental and educational needs that they cannot be accommodated in special education programs solely for children with deafness or children with blindness.”

This definition points to something important: deafblindness is not simply the sum of a hearing loss plus a vision loss. It is fundamentally a disability of information gathering. When two of a child’s three distance senses are impaired, the impact on learning, communication, and development is exponential.

Deafblindness is also far more diverse than many people realize. The majority of children with deafblindness have additional disabilities or health conditions:

- Approximately 90% have one or more additional disabilities or health issues
- 75% have two or more
- 50% have three or more

And for many of these children, their hearing and vision loss has not yet been recognized or addressed (NCDB, 2019).

Why Early Identification Matters

The earliest years of life are foundational. Physical, cognitive, social, and emotional development are deeply intertwined during this window — and for a child with deafblindness, disruptions in sensory access ripple across all of them.

Because vision and hearing are both limited, a child with deafblindness must rely on their contact senses, touch and taste to learn about their environment. Without intentional support, this means an enormous amount of the world stays out of reach.

Research is clear: early identification is positively correlated with a reduction in the negative impacts of combined sensory loss on future development (Bashinski, 2022).

Dual sensory loss can affect every area of a child's development, including:

- Sensory processing and integration
- Communication — both receptive and expressive
- Exploration, mobility, and participation
- Social relationships and friendships
- Concept development and visual and mental memory
- Incidental learning — the casual, background learning that sighted and hearing peers absorb constantly
- Independence

Early identification helps ensure that children receive the right support at the right time, including:

- Earlier treatment of sensory conditions to optimize remaining sensory function
- Appropriate developmental and academic interventions
- Access and communication strategies grounded in evidence-based practice
- Adaptive equipment and environmental modifications put in place proactively

How Do We Find These Children?

Early identification requires active, informed attention from the professionals and family members in a child's life. A few key starting points:

- Know the milestones for typical vision and auditory development, so that variations are recognizable.
- Review medical records carefully for any child suspected of hearing or vision concerns, including newborn hearing screening results.
- Be aware of syndromes, conditions, and risk factors commonly associated with deafblindness, such as CHARGE syndrome, Usher syndrome, prematurity, and congenital infections.

Who Can Help Identify Deafblindness?

No single professional holds the full picture. Identification and support require a coordinated team:

- Eye Care Specialists confirm visual diagnoses, functional status, treatment options, and prognosis.
- Audiologists confirm hearing status and evaluate options for listening devices and supports.
- School Personnel — including teachers of the visually impaired, orientation and mobility specialists, and educational audiologists — assess functional vision and hearing in real-world settings.
- Families bring irreplaceable knowledge of their child's daily behavior and responses.

Successful identification — and the transitions that follow — depend on respectful, careful collaboration across all these roles (Chen, 1997; Miles, 1995). Families face unique demands when a child has both a vision and hearing loss, and they deserve to be full partners in the process.

Take the Next Step

If you work with or care for young children and suspect a combined sensory loss, don't wait. Early action can significantly change a child's trajectory.

- Contact the Alaska Deafblind Project for guidance and resources. Our federally funded project is dedicated to supporting children with deafblindness and their families. You can reach us at: ablack@sesa.org or call: 907.334.1333.
- Use the NCDB's Early Identification and Referral Toolbox <https://www.nationaldb.org/national-initiatives/early/> as a practical starting point.
- Request a comprehensive evaluation that addresses both vision and hearing if there is any reason for concern.

References:

Bashinski, S. M. (2022, February 3). Early Identification of Children with Deaf-Blindness. Montana Deafblind Project, Rural Institute, University of Montana.

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Office of Special Education Programs. Deafblindness Identification & Referral Information.