



COMBINED VISION AND HEARING LOSS: UNDERSTANDING DEAFBLINDNESS

Meet Our Kids

In the mid to late 1960's, more than 3,000 children were born in the United States to mothers who had Rubella (German Measles) during pregnancy. This affected both the vision and hearing of these children and they were the first large group to be identified as "deafblind."

While Rubella is no longer a major medical problem in the United States, children continue to be identified with a combined vision and hearing loss due to increased survival of premature and low birth weight infants, as well as pre-natal, post-natal, and congenital conditions that affect vision and hearing.

Although the term deafblind implies a complete absence of hearing and sight, in reality, it refers to children with varying degrees of vision and hearing losses. The type and severity of losses differ from child to child. Even children who have the same condition causing their deafblindness will have very different amounts of usable vision and hearing. In addition, most children who are deafblind have other disabilities and many have complex health care needs. However, despite the broad diversity of the population, what these

children have in common is the need for specialized instruction to meet their unique learning needs.



The Continuum of Deafblindness

The most well-known person associated with the term "deafblindness" is Helen Keller. An infection at 18 months of age left her completely deaf and totally blind. While Helen Keller was "truly deafblind," she really only represents a small percentage of those who are classified as deafblind – about 6%.

There are actually five categories of vision and hearing impairments. All children who are deafblind can fall anywhere along a continuum made up of these five categories. The categories are:

- Visually Impaired and Hearing Impaired with Vision being the primary disability
- Visually Impaired and Hearing Impaired with Hearing being the primary disability
- Deaf and Visually Impaired
- Blind and Hearing Impaired
- Deaf and Blind

The Definition



Both the federal government and the state of Indiana have defined a combined vision and hearing loss using the term “deafblindness.” Both definitions are similar and include recognition of the unique nature of this population. The definitions basically state that a person is considered to be deafblind if:

He/she has both vision and hearing impairments, the combination of which creates such severe communication and other developmental and educational problems that the student cannot be accommodated in special education programs solely for students with hearing or visual impairments. (1999 IDEA Rules and Regulations 300.7(c)(2); 2002 Indiana Administrative Code 511 IAC 7-17 through 7-31).

This definition encompasses a complete range of hearing losses from mild to profound and vision losses from low vision to total blindness. In addition, often a child may have an impairment that only effects one eye or one ear or is diagnosed with a progressive loss that currently may not be a problem.

While the meaning of the definition has remained consistent, the terminology used to describe it has changed over time, depending upon the audience. Currently, the federal government uses

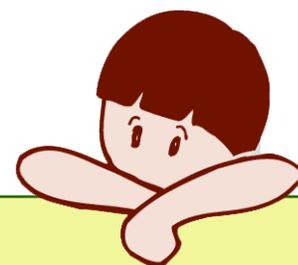
the term “deafblindness” to describe combined vision and hearing losses. In the state of Indiana, dual sensory impairment is the term used in the legal definition and, frequently, people will refer to dual sensory losses. “Deafblind” often is very difficult for families to hear and the term “dual sensory impairment” is often misunderstood. As a result, talking about combined vision and hearing loss allows us to be both more descriptive of the condition and more “family friendly.”

Additional Disabilities in Children who are Deafblind

It is important to remember that over 90% of the children reported nationally as deafblind have one or more additional disabilities. The following were reported among children with one or more additional disabilities:

- 66% cognitive disability
- 57% physical disability
- 38% complex health care needs
- 9% behavior challenges
- 30% other

Data from Killoran, J. (2007). The national Deafblind child count: 1998–2005 in review. Monmouth, OR: NTAC.



Reported Vision and Hearing Loss in Children Identified as Deafblind

Vision Loss

- 17% totally blind or light perception only
- 24% legally blind
- 21% low vision
- 17% cortical vision impairment
- 21% other

Hearing Loss

- 39% severe to profound hearing loss
- 13% moderate hearing loss
- 14% mild hearing loss
- 6% central auditory processing disorder
- 28% other

Data from Killoran, J. (2007). The national deafblind child count: 1998–2005 in review. Monmouth, OR: NTAC.

Sometimes Children who are Deafblind are Difficult to Spot . . .

It is clear that no single portrait can be painted to represent a child with deafblindness. Children who are deafblind are as varied as the number reported. The photographs and stories below illustrate this diversity. In addition, a list of some of the most common causes of combined vision and hearing losses also is included.

This is Melissa . . .



Melissa is 18 months old. She has had chronic inner ear infections and now has a severe sensorineural hearing loss. Melissa also has cerebral palsy, seizure disorders, impaired vision due to a diseased retina, and global developmental delays. Although it wasn't apparent at birth, she had Cytomegalovirus (CMV). Melissa is deafblind.

Say "Hi!" to Allie .

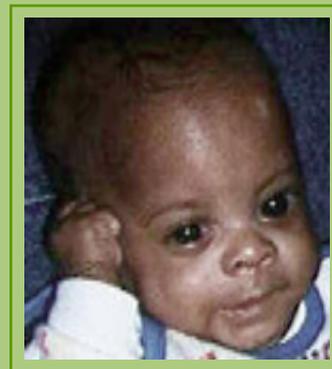


Allie is 3 years old. At the age of 1, tests showed that she had a moderate sensorineural hearing loss. She also has a coloboma in each eye; however, it has not been determined how much vision she has. In addition, Allie has blockages in her nasal passages, a heart defect and has always been small for her age. She has CHARGE Syndrome. Allie is considered deafblind.

Common Causes of Deafblindness:

CHARGE Syndrome
Cornelia de Lange Syndrome
Cri du chat Syndrome
Down Syndrome
Hurler Syndrome
Klippel-Feil Sequence
Leber Congenital Amaurosis
Trisomy 13
Trisomy 18
Usher Syndrome
Congenital Rubella
Congenital Toxoplasmosis
Cytomegalovirus (CMV)
Fetal Alcohol Syndrome
Hydrocephaly
Microcephaly
Asphyxia
Encephalitis
Infections
Meningitis
Severe Head Injury
Stroke
Prematurity (e.g., Low Birth Weight, Retinopathy of Prematurity)

Meet Josh . . .



Josh was born at 23 weeks and weighed 1 lb., 4 oz. He has a profound hearing loss. Josh has no vision in his left eye due to a detached retina; however, he seems to have some usable vision in his right eye. Now, at a year old, he doesn't crawl, but scoots on his back. Josh also is deafblind.

TA, TRAINING, & SUPPORT

Families and educators of infants, toddlers and children who are deafblind need to have access to training and support. Each state has a federally funded technical assistance project specifically designed to improve educational services, provide opportunities for training, and to help support families of children who are deafblind. For more information or to request services in Indiana contact:



Indiana Deafblind Services Project
Blumberg Center, COE/University Hall
401 N. 7th St, Room 009W
Terre Haute, IN 47809
1-800-622-3035

www.indstate.edu/blumberg/db/deafblind.htm

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KEY POINTS TO REMEMBER

- Deafblindness is varied and complex.
- Children with deafblindness are as diverse as the number of children reported.
- Early identification and intervention are essential.
- Children and youth who are deafblind often have other disabilities.
- Training and support are available through federally funded technical assistance projects in each state.

RESOURCES

Killoran, J. (2007). *The national deafblind child count: 1998–2005 in review*. Monmouth, OR: National Technical Assistance Consortium for Children and Young Adults who are DeafBlind (NTAC), Teaching Research Institute, Western Oregon University. Available at <http://nationaldb.org/NCDBProducts.php?prodID=57>

Kimberling, W. J. (2004). Genetic hearing loss associated with eye disorders. In H. V. Toriello, W. Reardon, & R. J. Gorlin (Eds.), *Hereditary hearing loss and its syndromes* (pp. 126–165). New York: Oxford University Press.

Brown, D., & Bates, E. (2005, Spring). A personal view of changes in deafblind population, philosophy, and needs. *DeafBlind Perspectives*, 12(3), 1–5.

For additional resources and information about deafblindness, go to www.nationaldb.org.



The purpose of the Indiana Deafblind Services Project's (INDBS) *The Sooner the Better Fact Sheets* is to increase knowledge of early intervention and early childhood education personnel, families, medical and community agency personnel about factors related to combined vision and hearing loss in young children.

