National Consortium On Deaf-Blindness

Children Who Are Deaf-Blind

Practice Perspectives - Highlighting Information on Deaf-Blindness Number 2 November 2007

The nature and extent of deaf-blindness in children is often misunderstood, but a new report, *The National Deaf-Blind Child Count: 1998–2005 in Review*, shines a light on this unique group of children. The review, which summarizes 8 years of data, not only provides a count of the number of children, from birth through age 21, who have been identified as deaf-blind in each state, but also reports other details about this population. These include the classification of vision and hearing loss, the types of additional disabilities that may be present, and the causes of deaf-blindness.

Although the term *deaf-blind* 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 differ from child to child. The key feature of deaf-blindness is that the combination of losses limits access to auditory and visual information.

Children with deaf-blindness require teaching methods that are different from those for children who have only hearing or vision loss. When *both* vision and hearing are affected, especially from birth or early in life, natural opportunities to learn and communicate can be severely limited.

More than 90% of children who are deaf-blind have one or more additional disabilities or health problems and some may be identified as having multiple disabilities rather than deaf-blindness. In these cases, the impact of combined hearing and vision loss may not be recognized or addressed.

Training and Support

It is critical that families and educators have access to training and support for the assessment and education of infants, children, and youth who are deaf-blind. Each state has a federally funded technical assistance project to provide this training and support. For information contact the National Consortium on Deaf-Blindness:

Phone: 800-438-9376 TTY: 800-854-7013
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Reported Vision and Hearing Loss in Children Identified as Deaf-Blind

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

Additional Disabilities in Children Who Are Deaf-Blind

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

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

Causes of Deaf-Blindness

There are many causes of deaf-blindness. Those that are present or occur around the time a child is born include prematurity, childbirth complications, and numerous congenital syndromes, many of which are quite rare. Deaf-blindness may also occur later in childhood or during adulthood due to causes such as meningitis, brain injury, or inherited conditions.

Many experts in the United States and other countries believe that the population of children who are deaf-blind has become more severely disabled over the past several decades. This may be due, in part, to advances in medical technology that have increased the survival rates for premature infants and children with very serious conditions, who are also deaf-blind.

However, deaf-blindness is not always associated with additional disabilities. For example, Usher Syndrome, an inherited condition that causes hearing loss and progressive vision loss, is not typically associated with other significant challenges.

Educational Settings

National Deaf-Blind Child Count data shows that although children who are deaf-blind are educated in a variety of settings, most are educated separately from students who do not have disabilities.

Infants and Toddlers
Seventy percent of children with deaf-blindness from birth through age 2 receive early intervention services at home. The rest are typically served in specialized settings such as hospitals, clinics, early intervention centers, and residential facilities.

Pre-school
Seventy-two percent of children aged 3 through 5 are in special education classrooms, separate schools, or residential facilities. Only 20% are in classrooms with young children who do not have disabilities, and 5% are educated at home.

School-age
Most children and youth aged 6 through 21 are also educated apart from students who do not have disabilities:

39% in separate classrooms
16% in separate public schools
10% in public or private residential facilities
8% in separate private schools
7% in hospitals or at home
5% in other settings

Only 15% are educated in regular classrooms and resource rooms.

Most Common Causes of Deaf-Blindness in Children in the U.S.

- Heredity
- Prematurity
- Prenatal complications
- Postnatal complications
- CHARGE Syndrome
- Microcephaly
- Cytomegalovirus
- Hydrocephaly
- Meningitis
- Usher Syndrome

Race/Ethnicity of Children Who Are Deaf-Blind

56%	White
14%	Black
12%	Hispanic and Latino
3%	Asian and Pacific Islander
2%	American Indian and Alaska Native
13%	Other

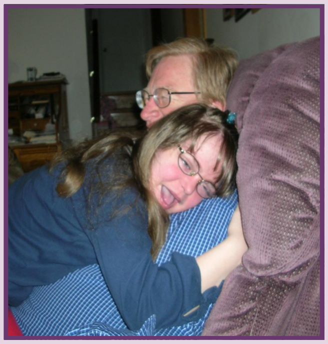
Data from Killoran, J. (2007). *The national deaf-blind child count: 1998–2005 in review.* Monmouth, OR: NTAC.

Profiles

In reviewing the National Deaf-Blind Child Count data submitted over the years, it is clear that no single portrait can be painted to represent a typical child with deaf-blindness. Children who are deaf-blind are as varied as the number reported. The photographs and stories below illustrate this diversity.

BJ, age 2½, is from Kosrae, an island in Micronesia. He now lives in Hawaii with his parents and sister and attends a special education preschool. He has a conductive hearing loss and vision loss caused by optic nerve damage. BJ loves to explore his environment and enjoys activities that involve movement, vibration, or rhythm. He likes to swing, jump, and wrestle. He also likes music (especially drums and keyboards) and toys that light up, make sounds, or vibrate.

Malik is 11 and lives in North Carolina. He has CHARGE Syndrome, a condition that can cause hearing loss, vision loss, other disabilities, and medical problems. Malik attends the Eastern North Carolina School for the Deaf, where he is in a special needs classroom. He is profoundly deaf and visually impaired. Malik uses American Sign Language to communicate, chooses his own meals, and even carries a wallet. He is known as the "Little King" to his family, teachers, and doctors, and with their love and support, he has thrived.



Brittany, age 14, lives with her grandparents in Pennsylvania. She was born prematurely, and she has cortical visual impairment and is deaf and developmentally delayed. Throughout her life, Brittany has had many health problems, including asthma, pneumonia, scoliosis, and kidney failure (she had a kidney transplant in 2003). She now attends Overbrook School for the Blind, and her goals are to live independently, find productive employment, and have an active social life. Brittany enjoys exploring things with her hands and other activities that take advantage of her sense of touch.

Divya is 21 and has Usher Syndrome. She has hearing loss, night blindness, and tunnel vision, which are all characteristic of this condition. Divya is fluent in American Sign Language (ASL) and has a cochlear implant. She lives in Florida, where she is a senior at her local high school. She is fully included and uses interpreters. When Divya graduates, she plans to attend a 2-year college and earn a degree or certificate in a field that will allow her to help people and use her ASL skills. Indian dance is one of her special interests. She won the best talent award two years in a row at the Florida School for the Deaf and the Blind (FSDB) Talent Show, and was also crowned Miss FSDB. She performed with other students at the Super Bowl in 2005.

National Deaf-Blind Child Count

Details about the population of children with deaf-blindness provide educators and policymakers with information to guide the development of services to meet the early intervention and educational needs of these children. The National Deaf-Blind Child Count has been conducted for the U.S. Department of Education's Office of Special Education Programs since 1986. The data are collected by state projects for children and youth who are deaf-blind and compiled by the National Consortium on Deaf-Blindness.

For more information go to:
www.nationaldb.org/TAChildCount.php

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Key Points

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

Resources

Killoran, J. (2007). *The national deaf-blind child count: 1998–2005 in review*. Monmouth, OR: National Technical Assistance Consortium for Children and Young Adults who are Deaf-Blind (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 deaf-blind population, philosophy, and needs. *Deaf-Blind Perspectives, 12*(3), 1–5.

For additional resources and information about children who are deaf-blind, go to www.nationaldb.org.

IDEAs that Work

The purpose of NCDB *Practice Perspectives* is to expand and broaden the use of current information resources by developing easily understandable products with accessible formats.

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