Who are Children Who are Deaf-Blind?

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The nature and extent of deaf-blindness in children is often misunderstood, but data collected by state deaf-blind projects and compiled annually by the National Consortium on Deaf-Blindness as the National Child Count of Children and Youth Who Are Deaf-Blind (NCDB, 2008), shines a light on this unique condition. The child count provides the number of children (age birth through 21) identified with deaf-blindness in each state, as well as information about a variety of characteristics of the population. This article summarizes key findings from a report that analyzed eight years of child count data (Killoran, 2007).

Although the term “deaf-blind” implies a complete absence of hearing and sight, it actually refers to individuals with varying degrees and types of vision and hearing losses as illustrated in (table 1). The key feature of deaf-blindness is that the combination of losses results in inadequate access to auditory and visual information. In addition to hearing and vision loss, more than 90% of children have one or more additional disabilities or health problems and 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. Deaf-blindness is not always associated with additional disabilities, however. For example, Usher Syndrome, an inherited condition that causes hearing loss and progressive vision loss, is not typically associated with other disabilities.

There are many causes of deaf-blindness as listed in table 2 (Killoran, 2007; Kimberling, 2004). Causes 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 of premature infants and of children with very serious disabilities, who also are deaf-blind.

Children with deaf-blindness require teaching methods that differ from those for children who have hearing loss or vision loss as single disabilities. When both vision and hearing are affected, especially if this occurs at birth or early in life, natural opportunities to learn and communicate are severely limited. 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. Most states have a technical assistance project funded by the U.S. Department of Education’s Office of Special Education Programs (OSEP) to provide this training and support. OSEP also funds the National Consortium on Deaf-Blindness, a national technical assistance and information dissemination project.

Children who are deaf-blind are educated in a variety of settings. Most, however, are educated separately from students who do not have disabilities and this situation has changed very little over the years.
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, or 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, age 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 home or hospitals

Only 15% are in regular education settings including regular classrooms and resource rooms.

Due to the complex nature of deaf-blindness, an understanding of the diversity of children who are deaf-blind is essential. The National Child Count of Children and Youth Who Are Deaf-Blind, conducted for OSEP since 1986, provides data that can be used by educators and policymakers to guide the development of services to meet the early intervention and educational needs of these children.

References


Table 1

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 or profound hearing loss
- 13% moderate hearing loss
- 14% mild hearing loss
- 6% central auditory processing disorders
- 28% other

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

Table 2

Most Common Causes of Deaf-Blindness in Children in the US

- Heredity
- Prematurity
- Pre-natal complications
- Post-natal complications
- CHARGE syndrome
- Microcephaly
- Cytomegalovirus
- Hydrocephaly
- Meningitis
- Usher Syndrome

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