

Educational Services and Programs for Children who are Deaf-Blind A Brief Overview of the Federal Program

Deaf-blindness is often described as an information gathering disability. People who are deaf-blind are not able to easily obtain information using the distance senses of hearing and sight and this impacts their ability to interact with others and learn about the world around them. For children who are deaf-blind, this has significant educational implications. They require unique instructional techniques and strategies in order to learn to communicate, develop concepts, gain mobility, and acquire independent living, academic, and vocational skills. Deaf-blind education is a unique specialization within the area of low incidence disabilities. Congress first recognized the need for specialized educational services for this population during the late 1960s and has supported programs for children who are deaf-blind ever since. Currently OSEP funds a number of programs including state deaf-blind technical assistance projects, a national technical assistance project, a national clearinghouse, several research projects, and support for personnel preparation.

Population and Characteristics

The current IDEA regulations provide the following federal definition of deaf-blindness:

“Deaf-blindness means concomitant hearing and visual impairments, the combination of which causes 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. [Code of Federal Regulations 300.7(c)(2)]

The 2004 National Deaf-Blind Child Count identifies approximately 9500 children (birth-21) as deaf-blind. Information for this count is collected annually by the state deaf-blind projects and compiled for OSEP by the National Technical Assistance Consortium on Children and Young Adults Who Are Deaf-Blind (NTAC). The count also collects data about various characteristics of children who are deaf-blind such as etiology, extent of vision and hearing loss, and educational setting. For the last ten years, the number of children identified as deaf-blind (birth-21) in the United States has stayed consistently around 10,000.

Deaf-blindness is caused by a wide variety of conditions that may be present at birth or acquired during the postnatal period or later in life. In many cases, the cause is unknown. Some of the most common known causes in children are prematurity, prenatal or postnatal complications, and a vast number of syndromes or genetic disorders. The majority of children also have physical or cognitive disabilities or complex medical needs and because of this are often not identified as deaf-blind by state education agencies. This multitude of factors—the severity of vision and hearing loss, the underlying cause of deaf-blindness, age of onset, and the likelihood and varied nature of additional disabilities—combine to create exceptionally complex educational needs. This underscores the need for specialized educational programs tailored to the unique needs of each child.

Early Federal Support

Prior to 1933, no formal education programs existed for people with deaf-blindness. From the 1930s to the 1950s, several states instituted programs in the form of residential schools for students with deaf-blindness. Throughout the 1950s and 1960s, most educational programs were provided at state residential schools for children who were either blind or deaf. These programs were few in number and scattered widely across the United States, limited in their enrollment only to those students who clearly indicated promise of academic achievement. Children were taught following traditional procedures that their teachers had found successful when instructing children without disabilities. In the 1950s in Australia and middle 1960s in the United States there was an epidemic of maternal rubella. In the United States, this epidemic caused the birth of an estimated 5,000 children with deaf-blindness and became the catalyst for the development of legislation that would establish services for children and youth who are deaf-blind in this country.

The international rubella epidemic of 1964-1965 greatly increased national awareness of the lack of academic programs for children with multiple disabilities. Many children were emerging from the epidemic with both deafness and blindness to confront an ill prepared and understaffed resource of trained service providers. With the enactment of the Elementary and Secondary Education Act of 1965 (PL 89-10), America had just begun to direct certain of its federal dollars to support programs for the educationally deprived. The Centers and Services for Deaf-Blind Children Program began in 1969 with a funding initiative of one million dollars. Ten regional centers were established to serve children and teachers. By 1976, the federal monies had increased to 16 million dollars in appropriated funds. In the 1980's those monies decreased to around 15 million dollars and in 1990 the amount again decreased to a little over 12 million dollars and, today, remains at that current level of funding.

The number of students served by funded programs increased from approximately 150 to more than 5,000 in the 1970s. During this time the network of multi state regional centers for deaf-blind children grew, providing a national network of communication and sharing for those serving the population. Centers were staffed by personnel with specific training in deaf-blindness, provided ongoing training and consultation and produced training materials that could be disseminated through the centers.

With the passage in 1975 of the Education of All Handicapped Children Act (PL 94-142), a new national dedication to meeting the needs of persons with disabilities, their parents, and service providers was declared. This law mandated states to provide a free, appropriate public education to all children with special needs. This resulted in the development of more local school district programs for all multiply handicapped children, including children who were deaf-blind. From this legislation came the amendments of 1983 and 1986 that shifted the emphasis of federally-funded programs for deaf-blind children from direct services to technical assistance and from regional centers to state programs. This, coinciding with the trend toward inclusive education,

dramatically changed the way children were educated. Now, rather than being educated in centralized locations, children were typically educated in their local communities and thus dispersed across many schools within each state.

States began accepting and acting upon a greater recognition of their responsibility for these children, while federal dollars were being directed toward carving out new techniques for teaching, researching cause and effect, conducting project assessments and disseminating and demonstrating strategies for the number and types of services provided to children with deaf-blindness under federal funding. With the enactment of the Individuals with Disabilities Education Act (1990) the federal program instituted new changes. This legislation specified the continuation of the program specific to deaf-blind children, defined the population, required funding under this section be specifically for this population, and outlined several new initiatives including a National Information Clearinghouse and direct services to children within “pilot projects”. Over the last 15 years, program monies have been used to fund state and national technical assistance projects, research projects, a national transition project, model and demonstration projects, the clearinghouse and some personnel preparation programs. Funding for the deaf-blind program has not increased in more than 15 years, and with children being served in districts all across the country, national and state projects remain a significant resource for these children and their families.

The deaf-blind technical assistance and information dissemination projects currently funded by OSEP make up a community of people and agencies dispersed across the country, working to help families, educators, and others provide high quality education and services for children who are deaf-blind. They work with a broad spectrum of individuals and agencies including general and special educators, family members, parent organizations, state education agencies, early childhood programs, and adult service agencies. Collaboration with all of these entities is crucial for developing a solid foundation of services for children who are deaf-blind and for children with other disabilities as well.

State and Multi-State Deaf-Blind Projects

These projects provide technical assistance and training to teachers and to other professionals and agencies involved with children and youth who are deaf-blind. They also provide services to families and are responsible for identifying children who are deaf-blind in their states. In general, there is one deaf-blind project in each state. One multi-state project serves four states in the New England region. Services offered vary by state and may include workshops and other types of training events, consultations, online courses, newsletters, opportunities for parent-to-parent contact, and family retreats. Many state projects collaborate with universities and teacher preparation programs to provide information to future teachers.

National Technical Assistance Consortium on Children and Young Adults Who Are Deaf-Blind (NTAC)

NTAC works individually with the state deaf-blind projects on specific activities that involve a variety of individuals in order to improve results and outcomes for children

and youth who are deaf-blind and their families. Technical assistance mechanisms include workshops, conferences, Webinars, Listservs, consultation, facilitation, product development, and national collaboration with other federal agencies. Individualized TA activities range from one-time workshops to long-term activities to more intensive systems change work that may take up to 2 years. National activities include an annual project director's meeting carried out on behalf of OSEP, an annual topical workshop, and an annual parent workshop co-sponsored with the National Family Association for Deaf-Blind. NTAC combines the resources and expertise of two major organizations, the Helen Keller National Center and Teaching Research at Western Oregon University.

Information Dissemination

DB-LINK, The National Information Clearinghouse on Children Who Are Deaf-Blind

DB-LINK makes relevant information about deaf-blindness available to parents, teachers, or anyone who is connected to a child or youth who is deaf-blind. Services include individual responses to requests for information, referrals, and in-depth research. DB-LINK works closely with both the state projects and NTAC to provide information needed to support their work. DB-LINK also maintains an extensive Web site with links to DB-LINK's publications database, information about many deaf-blind topics, research in deaf-blindness, and deaf-blind services and organizations throughout the U.S. The project has produced a number of publications. DB-LINK is a collaborative effort between 3 agencies: Teaching Research, Hilton/Perkins Program at Perkins School for the Blind, and the Helen Keller National Center.

2005

Information contained in this article was previously published in:

Counterpoint (newspaper of the National Association of State Directors of Special Education [NASDSE]) Fall, 2004. Peggy Malloy, *Educational Services, Programs for Children Who are Deaf-Blind*.

Welcoming Students Who are Deaf-Blind into Typical Classrooms, Haring, N. et al, 1995. Charles Freeman and Paul Thompson, *A History of Federal Supports for Students with Deaf-Blindness*.