Deaf-Blindness

✧ Introduction ✧

There are approximately 45,000 to 50,000 individuals in the U.S. who are deaf-blind.[1] According to the 2007 National Deaf-Blind Child Count, more than 10,000 are children under the age of 21.[2]

The word "deaf-blindness" may seem as if a person cannot hear or see at all. The term actually describes a person who has some degree of loss in both vision and hearing. The amount of loss in either vision or hearing will vary from person to person.

Our nation's special education law, the Individuals with Disabilities Education Act (IDEA), defines "deaf-blindness" as:

> ...concomitant [simultaneous] 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. [§300.8(c)(2)]

The National Consortium on Deaf-Blindness observes that the "key feature of deaf-blindness is that the combination of losses limits access to auditory and visual information."[3] This can severely limit an individual's natural opportunities to learn and communicate with others.

✧ Finding Help for Children with Deaf-Blindness ✧

Very young children (birth up to age 3) who are deaf-blind are typically eligible for *early intervention services* under the Infants and Toddlers with Disabilities program of IDEA (also called Part C). These services are extremely important to children with deaf-blindness and their families, for the services are designed to address the child's developmental and learning

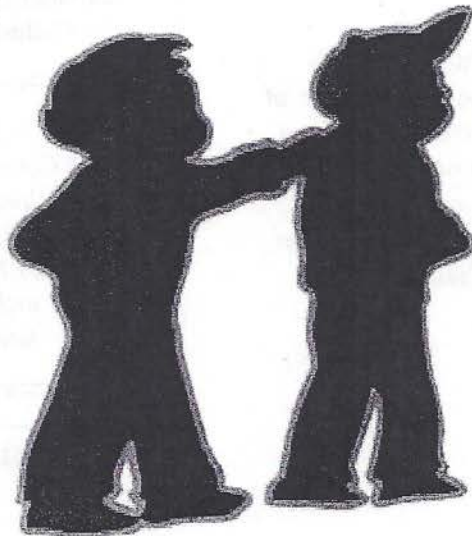**NICHCY** *is the National Dissemination Center for Children with Disabilities.*

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needs. Parents are involved in deciding what services their child and family need to address the challenges of deaf-blindness. Services are either provided free of charge to families or on a sliding cost scale based on the family's income. To find the early intervention program in your area, ask your pediatrician, get in touch with the pediatric unit of a nearby hospital, or take a look at NICHCY's State Resource Sheet for your state (online at: http://www.nichcy.org/Pages/StateSpecificInfo.aspx). We list the central contact for the early intervention system in every state. This office can put you in touch with a program near you.

When children with deaf-blindness reach the age of 3, they transition into *special education services* under Part B of IDEA. Special education services are provided free through the public school system. Even if a child with deaf-blindness is not in school yet (for example, a four-year-old), the school system is still responsible for making sure that special education and related services are available to the child. Because deaf-blindness causes severe communication and other developmental and educational needs, it's very important for children with deaf-blindness to receive special education and related services to address their individual needs. You can find out more about these services and how to access them by contacting the local elementary school in your area.

Rather than duplicate the excellent work of others, NICHCY is pleased to connect you with an array of information and assistance already available on deaf-blindness. What's listed below is not all that's out there, information-wise, but will certainly lead you to the founts of experience and knowledge that will be very helpful in addressing the challenges associated with deaf-blindness.

✧ About Deaf-Blindness ✧

- *FAQs about deaf-blindness.*
  www.aadb.org/FAQ/faq_DeafBlindness.html

- *Overview of deaf-blindness.*
  www.nationaldb.org/NCDBProducts.php?prodID=38

- *Children who are deaf-blind.* http://www.nationaldb.org/documents/products/population.pdf

- *Information about deaf-blindness.*
  Personal insights and information from an individual with deaf-blindness.
  www.deafblind.com/info-db.html

- *How do deaf-blind people communicate?*
  www.aadb.org/factsheets/db_communications.html

- *The Deafblind Manual Alphabet.*
  www.deafblind.com/card.html

- *Find what's out there on your topic.*
  Search the world's most comprehensive collection of books, articles, proceedings, videos, and other materials about deaf-blindness.
  http://www.nationaldb.org/ISLibrary.php

✧ Finding Services ✧

- *State deaf-blind projects.*
  Every state has a project that specializes in deaf-blindness. Find yours at the National Consortium on Deaf-Blindness.
  http://www.nationaldb.org/ppStateDBProjects.php

  - *Visit the American Association of the Deaf-Blind.*
    AADB provides a listing of state and local organizations for deaf-blind people and also a listing of service and rehabilitation agencies around the country.
    http://www.aadb.org/resources/resources.html

✧ The Experts on Deaf-Blindness ✧

- National Consortium on Deaf-Blindness (NCDB)
  http://www.nationaldb.org

- Helen Keller National Center for Deaf-Blind Youths and Adults (HKNC)
  http://www.hknc.org

- American Association of the Deaf-Blind (AADB)
  http://www.aadb.org

- Deafblind International
  http://www.deafblindinternational.org/

✧ In Children's Early Years ✧

- Early interactions with children who are deaf-blind.
  http://www.nationaldb.org/
  NCDBProducts.php?prodID=34

- Communication at home and in the community.
  Helpful strategies and suggestions from parents and families with a child who is deaf-blind.
  http://www.nationaldb.org/documents/products/
  parent99.pdf

- Communication factsheets for parents.
  http://www.nationaldb.org/documents/products/
  communication-a.pdf

- Talking the language of the hands to the hands.
  This publication examines the importance of hands for the person who is deaf-blind, reviews hand development, and identifies specific teaching skills that facilitate hand development and expressiveness in persons who are deaf-blind.
  http://www.nationaldb.org/
  NCDBProducts.php?prodID=47

- The intervener in early intervention and educational settings for children with deaf-blindness.
  http://www.nationaldb.org/
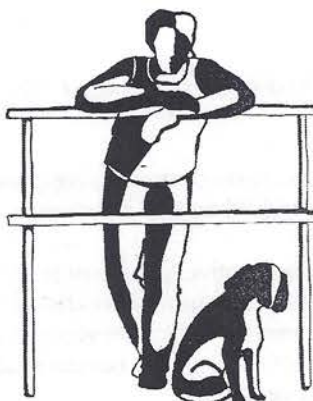 documents/products/
  intervener.pdf

✧ School Matters ✧

- Considerations when teaching students who are deaf-blind (NETAC Teacher Tipsheet).
  http://pdcorder.pepnet.org/
  media/1011TPSHT_
  Deaf_Blind.pdf

- Deaf-blindness: Educational service guidelines.
  This best practice guide is designed to help states, districts, schools and practitioners in supporting students who are deaf-blind and their families. Copies may be purchased at www.perkins.org/publications for $25.00 a copy.

- Teacher packet.
  A selection of articles, fact sheets, bibliographies, and state resources organized to provide information for the teacher who is new to the deaf-blind student.
  http://www.nationaldb.org/
  NCDBProducts.php?prodID=48

✧ Transition to Adulthood for Students with Deaf-Blind ✧

- Transition planning for students with deaf-blindness.
  http://nationaldb.org/documents/products/
  transition01-09.pdf

- More on transition planning: Coaching for students, parents, and professionals.
  http://centerondeafness.utk.edu/pec/
  transition%20planning%20for%20deafblind.pdf

- Self-determination for students who are deaf-blind.
  http://www.nationaldb.org/documents/products/
  self-determ.pdf

- National Transition Follow-Up Study of Youth Identified as Deaf-blind: Parent Perspectives.
  http://www.nationaldb.org/documents/
  products/transition.PDF

✧ For Administrators ✧

- *Deaf-Blind Child Counts: Issues and challenges.*
  http://www.projectforum.org/docs/Deaf-BlindChildCounts-IssuesandChallenges.pdf

- *National Deaf-Blind Child Counts.*
  The National Deaf-Blind Child Count, reported by each state's Project for Children and Youth who are Deaf-Blind, is collected annually on December 1 of each year and is a "snapshot" of the characteristics, educational settings and living arrangements of children and youth who fit the state project's definition of being deaf-blind as of that date. The Annual Reports from 2001 through 2006 are available in PDF.
  www.nationaldb.org/TAChildCount.php#Summaries

- *Psychological evaluation of children who are deaf-blind.*
  This fact sheet provides answers to frequently asked questions about psychological evaluations for infants, children, and adults who are deaf-blind.
  www.nationaldb.org/NCDBProducts.php?prodID=40

- *Recommendations on the training of interveners for students who are deaf-blind.*
  http://www.dblink.org/pdf/intervener-train.pdf

- *Service delivery in rural areas.*
  Here's a manual or blueprint for rural agencies to develop deaf-blind services in their local areas.
  http://pdcorder.pepnet.org/media/1180LinkByLink.pdf

✧ Resources in Spanish ✧

- Visit the National Consortium on Deaf-Blindness, where you'll find many fact sheets and other resources available in Spanish.
  http://www.nationaldb.org/ISProductos.php

- *English/Spanish Specialized Deaf-Blind Glossary/ Espanol Glosario Especializado En Sordoceguera.*
  http://www.nationaldb.org/documents/products/esgloss.pdf

✧ References ✧

[1] Gallaudet University. (2004). FAQ: *Deaf-blind in the U.S.* Retrieved February 19, 2009, from: http://library.gallaudet.edu/Library/Deaf_Research_Help/Frequently_Asked_Questions_(FAQs)/Statistics_on_Deafness/Deaf-Blind_in_the_US.html

[2] National Consortium on Deaf-Blindness. (2008, September). *The 2007 national child count of children and youth who are deaf-blind.* Retrieved February 19, 2009, from: http://www.nationaldb.org/documents/products/2007-Census-Tables.pdf

[3] National Consortium on Deaf-Blindness. (2007, November). *Children who are deaf-blind.* Retrieved February 19, 2009, from: www.nationaldb.org/documents/products/population.pdf

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