This overview provides basic information on the causes of deaf-blindness and the particular challenges faced by individuals with deaf-blindness. Causes of deaf-blindness include various syndromes, multiple congenital anomalies, prematurity, congenital prenatal dysfunction, and various postnatal causes. Differences between people deaf-blind from birth and those adventitiously deaf-blind are noted. Challenges facing a person who is deaf-blind are identified, especially the learning of language and mobility skills. Challenges facing the family, teachers, and caregivers are also discussed and suggestions are given in the areas of communication, orientation and mobility, individualized education, transition, and inclusion within the family. The paper stresses that deaf-blind individuals have a unique and valuable experience of the world and can have a high quality life if they accept their condition, are provided educational experiences which help them maximize their abilities, and live in accepting families and communities. Also provided is a descriptive guide to 7 organizations that offer help to families, caregivers, and teachers and an annotated list of 10 print resources. (DB)
Overview on Deaf-Blindness

By Barbara Miles

What Is Deaf-Blindness?

It may seem that deaf-blindness refers to a total inability to see or hear. However, in reality deaf-blindness is a condition in which there is a combination of visual and hearing impairments that cause "such severe communication and other developmental and learning needs that the persons cannot be appropriately educated in special education programs solely for children and youth with hearing impairments, visual impairments or severe disabilities, without supplementary assistance to address their educational needs due to these dual, concurrent disabilities" (1990, IDEA, Sec. 622). Children who are called deaf-blind are singled out educationally because impairments of sight and hearing require thoughtful and unique educational approaches in order to ensure that children with this disability have the opportunity to reach their full potential.

A person who is deaf-blind has a unique experience of the world. For people who can see and hear, the world extends outward as far as his or her eyes and ears can reach. For the young child who is deaf-blind, the world is initially much narrower. If the child is profoundly deaf and totally blind, his or her experience of the world extends only as far as the fingertips can reach. Such children are effectively alone if no one is touching them. Their concepts of the world depend upon what or whom they have had the opportunity to physically contact.

If a child who is deaf-blind has some usable vision and/or hearing, as many do, her or his world will be enlarged. Many children called deaf-blind have enough vision to be able to move about in their environments, recognize familiar people, see sign language at close distances, and perhaps read large print. Others have sufficient hearing to recognize familiar sounds, understand some speech, or develop speech themselves. The range of sensory impairments included in the term "deaf-blindness" is great.

Who Is Deaf-Blind, and what are the Causes of Deaf-Blindness?

As far as it has been possible to count them, there are about 10,000 children (ages birth to 22 years) in the United States who have been classified as deaf-blind (Baldwin, 1994). It has been estimated that the adult deaf-blind population numbers 35-40,000 (Watson, 1993). The causes of deaf-blindness are many. Below is a list of many of the possible etiologies of deaf-blindness.

Major Causes of Deaf-Blindness

Syndromes
- Down
- Usher

Multiple Congenital Anomalies
- CHARGE Association
- Fetal alcohol syndrome
- Hydrocephaly
- Maternal drug abuse
- Microcephaly

Prematurity

Congenital Prenatal Dysfunction
- AIDS
- Herpes
- Rubella
- Syphilis
- Toxoplasmosis

Post-natal Causes
- Asphyxia
- Encephalitis
- Head injury/trauma
- Meningitis
- Stroke

Adapted from Etiologies and Characteristics of Deaf-Blindness Heller & Kennedy,(1994), p. viii, Table 1.
Some people are deaf-blind from birth. Others may be born deaf or hard-of-hearing and become blind or visually impaired later in life; or the reverse may be the case.

Still others may be adventitiously deaf-blind—that is, they are born with both sight and hearing but lose some or all of these senses as a result of accident or illness.

Deaf-blindness is often accompanied by additional disabilities. Causes such as maternal rubella can also affect the heart and the brain. Some genetic syndromes or brain injuries that cause deaf-blindness may also cause developmental delays and/or physical disabilities.

What are the Challenges Facing a Person who is Deaf-Blind?

A person who is deaf-blind must somehow make sense of the world using the limited information available to him or her. If the person’s sensory disabilities are great, and if people in the environment have not made an effort to order the world for him or her in a way that makes it easier to understand, this challenge may be overwhelming. Behavioral and emotional difficulties often accompany deaf-blindness and are the natural outcomes of the child’s or adult’s inability to understand and communicate.

People who can see and hear often take for granted the information that those senses provide. Events such as the approach of another person, an upcoming meal, the decision to go out, a change in routine are all signaled by sights and sounds that allow a person to prepare for them. The child or adult who misses these cues because of limited sight and/or hearing may come to experience the world as an unpredictable, and possibly threatening, place. To a great extent, persons who are deaf-blind must depend upon the good will and sensitivity of those around them to make their world safe and understandable.

The challenge of learning language is perhaps the greatest one that children who are deaf-blind face. It is also the greatest opportunity, since language holds the power to make their thoughts, needs, and desires known. The ability to use words can also open up worlds beyond the reach of their fingertips through the use of interpreters, books, and an ever-increasing array of electronic communication devices. In order to learn language, children who are deaf-blind must depend upon others to make language accessible to them. Given that accessibility, children who are deaf-blind face the challenges of engaging in interactions to the best of their abilities and of availing themselves of the language opportunities provided for them.

A person who is deaf-blind also faces, further, the challenge of learning to move about in the world as freely and independently as possible. Adult individuals also must eventually find adult living and work situations that allow them to use their talents and abilities in the best way possible. Many adults who are deaf-blind lead independent or semi-independent lives and have productive work and enjoyable social lives. The achievement of such success depends in large part not only on the severity of their impairments but also upon the education they have received, since childhood, and particularly upon the communication with others that they have been able to develop.

What are the Particular Challenges Facing the Family, Teachers and Caregivers of a Person who is Deaf-Blind?

Communication

The disability of deaf-blindness places unique demands upon families, teachers, and caregivers who must make sure that the person who is deaf-blind has access to the world beyond the limited reach of his or her eyes, ears, and fingertips. The people in the environment of children or adults who are deaf-blind must seek to include them—moment-by-moment—in the flow of life and in the physical environments that surround them. If they do not, the child will be isolated and will not have the opportunity to grow and to learn. If they do, the child will be afforded the opportunity to develop to his or her fullest potential.

The most important challenge for parents, caregivers, and teachers is to communicate meaningfully with the child who is deaf-blind. Continual good communication will help foster his or her healthy development. Communication involves much more than mere language. Good communication carries meaning. Good communications employ body language and gestures, as well as both signed and spoken words. A conversation with a child who is deaf-blind can begin with a partner who simply notices what the child is paying attention to at the moment and finds a way to let the child know that his or her interest is shared.

This shared interest, once established, can become a topic around which a conversation can be built. Mutual conversational topics are typically established between a parent and a sighted or hearing child by making eye contact and by gestures such as pointing or nodding, or by exchanges of sounds and facial expressions. Lacking significant amounts of sight and hearing, children who are deaf-blind will often need touch in order for them to be sure that their partner shares their focus of attention. The parent or teacher may, for example, touch an interesting object along with the child in a
nondirective way. Or, the mother may imitate a child's movements, allowing the child tactual access to that imitation, if necessary. (This is the tactual equivalent of the actions of a mother who instinctively imitates her child's babbling sounds.) Establishing a mutual interest like this will open up the possibility for conversational interaction.

Teachers and parents can continue conversations with children who are deaf-blind by learning to pause after the initial topic has been established. These children frequently have very slow response times. Respecting the child's own timing is crucial to establishing successful interactions. Pausing long enough to allow the child to take another turn in the interaction, then responding to that turn, pausing again, and so on—this back-and-forth exchange becomes a conversation. Such conversations, repeated consistently, build relationships and become the eventual basis for language learning.

As the child who is deaf-blind becomes comfortable interacting nonverbally with others, she or he becomes ready to receive some form of symbolic communication as part of those interactions. Often it is necessary to precede the introduction of words with the use of simple gestures and/or objects which serve as symbols or representations for activities. Doing so may help a child develop the understanding that one thing can stand for another.

Think of the many thousands of words and sentences that most children hear before they speak their own first words. A child who is deaf-blind needs comparable language stimulation, adjusted to his or her ability to receive and make sense of it. Parents, caregivers, and teachers face the challenge of providing an environment rich in language that is meaningful and accessible to the child who is deaf-blind. Only with such a rich language environment will the child have the opportunity to acquire language herself or himself. Those around the child can create a rich language environment by continually commenting on the child's own experience using sign language, speech, or whatever symbol system is accessible to the child. These comments are best made during conversational interactions. A teacher or a parent may, for example, use gesture or sign language to name the object that he or she and the child are both touching, or name the movement that they share. This naming of objects and actions, done many, many times, may begin to give the child who is deaf-blind a similar opportunity afforded to the hearing child—that of making meaningful connections between words and the things for which they stand.

Principal communication systems for persons who are deaf-blind are these:

- touch cues
- object symbols
- sign language
- Signed English
- gestures
- picture symbols
- fingerspelling
- Tadoma method of speech reading
- American Sign Language
- lip-reading speech
- Braille writing and reading
- large print writing and reading

Along with nonverbal and verbal conversations, a child who is deaf-blind needs a reliable routine of meaningful activities, and some way or ways that this routine can be communicated to her or him. Touch cues, gestures, and use of object symbols are some typical ways in which to let a child who is deaf-blind know what is about to happen to her or him. Each time before the child is picked up, for example, the caregiver may gently lift his or her arms a bit, and then pause, giving the child time to ready herself or himself for being handled. Such consistency will help the child to feel secure and to begin to make the world predictable, thus allowing the child to develop expectations. Children and adults who are deaf-blind and are able to use symbolic communication may also be more reliant on predictable routine than people who are sighted and hearing. Predictable routine may help to ease the anxiety which is often caused by the lack of sensory information.

Orientation and Mobility

In addition, the child who is deaf-blind will need help learning to move about in the world. Without vision, or with reduced vision, he or she will not only have difficulty navigating, but may also lack the motivation to move outward in the first place. Helping a young child who is deaf-blind learn to move may begin with thoughtful attention to the physical space around him or her (crib or other space) so that whatever movements the child instinctively makes are rewarded with interesting stimulation that motivates further movement. Orientation and mobility specialists can help parents and teachers to construct safe and motivating spaces for the young child who is deaf-blind. In many instances children who are deaf-blind may also have additional physical and health problems that limit their ability to move about. Parents and teachers may need to include physical and occupational therapists, vision teachers, health professionals, and orientation and mobility specialists on the team to plan accessible and motivating spaces for these children. Older children or adults who have lost vision can also use help from trained specialists in order to achieve as much confidence and independence as possible in moving about in their world.

Individualized Education

Education for a child or youth with deaf-blindness needs to be highly individualized; the limited channels available for learning necessitate organizing a program for each child that will address the child's unique ways of learning and his or her own interests. Assessment is crucial at every step of the
way. Sensory deficits can easily mislead even experienced educators into underestimating (or occasionally overestimating) intelligence and constructing inappropriate programs.

Helen Keller said, "Blindness separates a person from things, but deafness separates him from people." This potential isolation is one important reason why it is necessary to engage the services of persons familiar with the combination of both blindness and deafness when planning an educational program for a child who is deaf-blind. Doing so will help a child or youth with these disabilities receive an education which maximizes her or his potential for learning and for meaningful contact with her or his environment. The earlier these services can be obtained, the better for the child.

Transition

When a person who is deaf-blind nears the end of his or her school-based education, transition and rehabilitation help will be required to assist in planning so that as an adult the individual can find suitable work and living situations. Because of the diversity of needs, such services for a person who is deaf-blind can rarely be provided by a single person or agency; careful and respectful teamwork is required among specialists and agencies concerned with such things as housing, vocational and rehabilitation needs, deafness, blindness, orientation and mobility, medical needs, and mental health.

The adult who is deaf-blind must be central to the transition planning, whenever possible. The individual's own goals, directions, interests, and abilities must guide the planning at every step of the way. Skilled interpreters, family members and friends who know the person well can help the adult who is deaf-blind have the most important voice in planning his or her own future.

Inclusion in Family

Clearly, the challenges for parents, teachers and caregivers of children who are deaf-blind are many. Not least among them is the challenge of including the child in the flow of family and community life. Since such a child does not necessarily respond to care in the ways we might expect, parents will be particularly challenged in their efforts to include her or him. The mother or father of an infant who can see is usually rewarded with smiles and lively eye contact from the child. The parent of a child who is deaf-blind must look for more subtle rewards: small hand or body movements, for instance, may be the child's way of expressing pleasure or connection. Parents may also need to change their perceptions regarding typical developmental milestones. They can learn, as many have, to rejoice as fully in the ability of their child who is deaf-blind to sign a new word, or to feed herself, or to return a greeting as they do over another child's college scholarship or success in basketball or election to class office.

Parents, then, may need to shift expectations and perceptions in significant ways. They also need to do the natural grieving that accompanies the birth of a child who is disabled. Teachers and caregivers must also make these perceptual shifts. Parents' groups and resources for teachers can provide much-needed support for those who live and work with children and adults who are deaf-blind. Such supports will help foster the mutually rewarding inclusion of children who are deaf-blind into their families and communities. (See section below for resources.)

Summary

Though deaf-blindness presents many unique challenges to both those who have visual and hearing impairments and to their caregivers and friends, these challenges are by no means insurmountable. Many persons who are deaf-blind have achieved a quality of life that is excellent. The persons who are deaf-blind who have high quality lives have several things in common. First, they have each, in their own way, come to accept the absence of sight and hearing as a life situation which gives them a unique and valuable experience of the world. This fundamental acceptance can occur regardless of the severity of the particular sensory losses or other challenges that a person has. Second, they have had educational experiences which have helped them maximize their abilities to communicate and to function productively. Finally, these happy, involved persons who are deaf-blind live in families, communities, or social groups that have an attitude of welcoming acceptance. They have friends, relatives, and co-workers who value their presence as individuals with significant contributions to make to the world around them. For these persons with limited sight and hearing, and for those near them, deaf-blindness fosters opportunities for learning and mutual enrichment.

References


What Help is Available for Families, Caregivers and Teachers of Children and Adults who are Deaf-Blind?

American Association of the Deaf-Blind (AADB)
814 Thayer Ave, Ste 302
Silver Spring, MD 20910
TTY: (301) 588-6545
Fax: (301) 588-8705

AADB is a national consumer advocacy organization for people who have combined hearing and vision impairments. AADB is open to persons who are deaf-blind and individuals directly concerned with their well being, including spouses, children, friends, and health care professionals. It seeks to encourage independent living for deaf-blind individuals. The organization also provides technical assistance to persons who are deaf-blind and their families, educators, and service providers.

DB-LINK: National Information Clearinghouse On Children Who Are Deaf-Blind
Teaching Research
345 N. Monmouth Ave.
Monmouth, OR 97361
(800) 438-9376
TTY: (800) 854-7013
Fax: (503) 838-8150
Internet: leslieg@fsa.wosc.osshe.edu

DB-LINK is a federally funded information clearinghouse that identifies, coordinates, and disseminates information related to children (0-21) who are deaf-blind. DB-LINK provides free individualized information and referral services across many topics including effective early intervention, special education and general education practices, medical, health, social, recreational services, legal issues, employment and independent living, postsecondary educational services, and information on the nature of deaf-blindness. In addition, fact sheets are developed on selected topics. These too are available at no cost. Parents, professionals, employers, and other members of the public are encouraged to contact DB-LINK.

Helen Keller National Center For Deaf-Blind Youths And Adults (HKNC)
111 Middle Neck Road,
Sands Point, NY 11050-1299
(516)944-8900
TTY: 516/944-8637
Fax: 516-944-7302

HKNC is a national program which provides diagnostic evaluation, short-term comprehensive rehabilitation and personal adjustment training, and work experience and placement to youth and adults with deaf-blindness. Clients entering the HKNC program participate in a 10 week diagnostic evaluation. Goals are then set for each person based on this evaluation and input from the client, family, and sponsoring agency. Evaluation and training include the following areas: daily living skills, home management, orientation and mobility, communication, low vision, audiology, speech-language training, career exploration, employment training and experience, problem solving, recreation and leisure, creative arts and horticulture. Support services include medical, psychological, behavior management, case management, job, and residential placement. Client training is usually funded by the Department of Rehabilitation of the client's state. The Center also offers training in the field and at headquarters to new and prospective professionals who plan to work with the deaf-blind population. The Technical Assistance Center (TAC) assists in the transition of young adults who are deaf-blind as they move from education to adult life in the community. It provides training and technical assistance in comprehensive transition services to education and adult service agencies, parents and family members, and state and local interagency teams. HKNC also has a program of services for elderly adults with deaf-blindness. HKNC operates an extensive nationwide network of field services through its 10 regional offices and its 39 affiliated programs. The regional offices provide consultation and technical assistance to persons with deaf-blindness and their families and to public and private agencies in their regions. They locate, assist, and refer individuals who are deaf-blind to the most appropriate program for services.

Hilton/Perkins Program
Perkins School for the Blind
175 N. Beacon Street,
Watertown, MA 02172
(617) 972-7220
Fax: (617) 923-8076

Hilton/Perkins Program provides consultation, training and technical assistance to programs throughout the nation and in developing countries. Emphasis is on program development for multi-handicapped blind and deaf-blind infants, toddlers, and school-aged children. Funding is provided to organizations of parents, and to assist in the pre-service training of teachers. The Program gathers data, disseminates information and develops curricula and materials for parents and professionals. Staff organize and carry out regional training and national conferences. Support to parents is offered primarily through the support of national self-advocacy organizations such as the
National Association of Parents of the Visually Impaired (NAPVI) and the National Family Association for Deaf-Blind (NFADB), and their respective state chapters. The Program offers financial support, inservice training and materials development for parent organizations. Funding of teacher training in deaf-blindness is made through direct grants to selected colleges and universities. Internationally, the program assists in the development of educational services for children who are deaf-blind and multihandicapped blind in developing countries. Selected programs are supported in the Asia-Pacific Region, Africa, the Caribbean, Latin America, and Eastern Europe. Support includes assistance with program development, training and technical assistance for staff, and leadership training in the U.S.

National Family Association for Deaf-Blind (NFADB)

111 Middle Neck Road
Sands Point, NY 11050
(800) 255-0411 x275

NFADB is a national network of families who focus on issues surrounding deaf-blindness. As a national organization, NFADB advocates for all persons who are deaf-blind, supports national policy to benefit people who are deaf-blind, encourages the founding and strengthening of family organizations in each state, provides information and referrals, and collaborates with professionals who work with persons who are deaf-blind. The organization has representatives in each of its 10 regional districts throughout the country. It also publishes a quarterly newsletter.

Teaching Research Assistance To Children And Youth Experiencing Sensory Impairments (TRACES)

Western Oregon State College
345 N. Monmouth
Monmouth, OR 97361
(503) 838-8607

TRACES is a federally funded program dedicated to improving the quality of existing services for children with deaf-blindness. Through state and multistate “Services to Children who are Deaf-Blind” projects, technical assistance is provided to individuals, projects, agencies, or organizations utilizing the expertise of a large number of organizations, professionals, and consumer groups.
Additional Resources


This manual gives insight, information, and strategies for intervention to service providers for infants, toddlers, and preschool age children who are deaf-blind. The manual is divided into fourteen sections containing topic information specific to deaf-blindness. These topics include: basic information about deaf-blindness and the need for appropriate intervention; learning problems; information about hearing loss and auditory development; vision loss and stimulation; touch and tactile stimulation; daily care and self-help skills; massage techniques; fine and gross motor skills, and positioning and handling techniques; orientation and mobility; social and emotional development, and behavior issues; special health care needs including massage; ideas regarding play and toys. Order information: (801) 752-9533.


This book for interpreters, teachers, and other professionals who work with deaf-blind people. It provides basic information about deaf-blindness and devotes a large section to interpreting. The appendices cover organizations, agencies, and schools serving deaf-blind people; training for teachers and interpreters; manual and braille alphabets; and characteristics of vision loss; recommendations for those looking for more information. May be ordered in regular or large print format from the College for Continuing Education, Gallaudet University, 800 Florida Ave. N.E., Washington, D.C. 20002-3695.


This is a very readable presentation of deaf-blindness designed to give the reader a greater understanding of deaf-blindness and the related concerns and issues. It is based on the etiologies of deaf-blindness and is accompanied by numerous biographical sketches, charts, diagrams, tables, and photographs. It also includes an extensive and up-to-date bibliography. To order: Indiana Deaf-Blind Services Project, Blumberg Center, School of Education 502, Indiana State University, Terre Haute, IN 47809.


By using person-centered planning, service providers and family members can incorporate a deaf-blind individual's strengths, needs, and goals into a blueprint for life in the community. The guide describes how to secure the necessary supports—optimal health care, enhanced communication skills, and improved orientation and mobility—and encourages those involved in the transition process to move beyond traditional options. Topics include shared and consumer-owned housing, job skills, networking for employment, recreation and leisure activities, and opportunities for community inclusion.


This book is intended for parents but will also provide insight for others who share in the care and education of children who are deaf-blind. It provides explanations of the functions of vision and hearing and how they effect visual and auditory skills. The program itself is divided into six stages with no age reference because progress is continuous at each child's own rate. A milestone schedule of child development is provided as a guideline, along with appendices of sources of further information and resources.


This text combines some introductory materials, a historical perspective of services for students who are deaf-blind, and a selection of strategies for preparing teachers and students without disabilities to include students who are deaf-blind. Procedures for building social and communicative skills are discussed as well as broad guidelines for implementing behavioral support strategies, adapting environments, and providing instruction in natural settings. Current issues relevant to inclusion are
considered and essential values are highlighted that serve as the fundamental basis for bringing all students into the classrooms and communities where they reside.


A reference guide for teachers, parents, and paraprofessionals working or living with children who are deaf-blind. Provides day-to-day guidance and suggestions about techniques for assessing and for devising programs. Provides overviews on communication, motor development, perceptual development, and on orientation and mobility. Available in Spanish.


Papers of the National Symposium on Children and Youth who are Deaf-Blind, an endeavor at Transdisciplinary Partnership. This symposium was held to identify critical issues and "best practices" in providing services for individuals who are deaf-blind and to develop strategies for future actions. The symposium focused on several specific topical areas in an effort to find ways in which resources might be marshaled at the federal, state, local, family, and personal levels to address the issues collectively.

Barbara Miles is a communication specialist/consultant and teacher, experienced with all ages and levels of persons who are deaf-blind. She has taught regional, national and international seminars on communication issues for children who are deaf-blind. Her articles have been published in the Journal of Vision Impairments and Blindness, Deafblind Education, and regional newsletters.


This book is a practical guide based on experience and observation. It is intended for people who know sign language, who are already experienced in "deafness" and in interacting with deaf people, and who want to know more about "deaf-blindness" and interpreting for deaf-blind people. The book may be ordered from Sign Media, Inc., 4020 Blackburn Lane, Burtonsville, MD 20866 or by calling (301) 421-0268.


This book was written to help service providers working with persons who are deaf-blind. There are numerous examples from actual experience and discussions of practical applications. Sections on service needs, communication, orientation and mobility, sensory deprivation and a survey of dog guide schools. Available from AFB Press, (212) 620-2000 (voice) or (212) 620-2158 (TTY). Specify print or braille.