DB – LINK

The National Information Clearinghouse
On Children Who Are Deaf-Blind

Helen Keller National Center
Hilton/Perkins Program Perkins School for the Blind
Teaching Research Institute

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Overview on Deaf-Blindness

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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 the combination of hearing and visual losses in children cause "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" (34 CFR 300.8 (c) (2), 2006) or multiple disabilities. 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 over 10,000 children (ages birth to 22 years) in the United States who have been classified as deaf-blind (NCDB, 2008). 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
- Trisomy 13
- 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 cognitive disabilities 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 to communicate is perhaps the greatest one that children who are deaf-blind face. It is also the greatest opportunity, since communication and language hold 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 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 presents unique challenges to 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 can best be thought of as conversation. Conversations 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, parents, siblings, and peers can continue conversations with children who are deaf-blind by learning to pause after each turn in the interaction to allow time for response. 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 helpful to accompany the introduction of words (spoken or signed) 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, and will also enable him or her to anticipate events.

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
- gestures
- picture symbols
- fingerspelling
- Signed English
- braille writing and reading
- American Sign Language
- lip-reading speech
- Pidgin Signed English
- Tadoma method of speech 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. 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 themselves as individuals who have unique experiences of the world, and valuable gifts to share. This fundamental acceptance of self 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

The National Consortium on Deaf-Blindness (2008). 2007 National child count of children and youth who are deaf-blind. Monmouth: Teaching Research Division.

Wolff Heller, K. & Kennedy, C. (1994). Etiologies and characteristics of deaf-blindness. Monmouth: Teaching Research Publications.

Watson, D., & Taff-Watson, M. (Eds.), (1993). Second edition. A model service delivery system for persons who are deaf-blind. Arkansas: University of Arkansas

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

American Association of the Deaf-Blind (AADB)

8630 Fenton Street, Suite 121
Silver Spring, MD 20910-3803
TTY (301) 495-4402, Voice (301) 495-4403
Fax (301) 588-8705
aadb-info@aadb.org
http://www.aadb.org

AADB is a national consumer advocacy organization that promotes better opportunities and services for deaf-blind people.

Helen Keller National Center for Deaf-Blind Youths and Adults (HKNC)

141 Middle Neck Road
Sands Point, NY 11050-1299
Phone (800) 255-0411 ext. 326, Fax (516) 944-7302
TTY (516) 944-8900 ext. 326
hkncinfo@hknc.org
http://www.hknc.org

HKNC is a national program that provides evaluation, short-term comprehensive vocational rehabilitation training, work experience training and assistance to deaf-blind clients for job and residential placements.

National Consortium on Deaf-Blindness (NCDB)

Teaching Research Institute
345 N. Monmouth Ave.
Monmouth, OR 97361
Phone (800) 438-9376, Fax (503) 838-8150
TTY (800) 854-7013
info@nationaldb.org
http://www.nationaldb.org

NCDB works collaboratively with families, federal, state and local agencies to provide technical assistance, information and personnel training. NCDB brings together the resources of three agencies with long histories of expertise in the field of deaf-blindness and is home to DB-LINK.

National Family Association for Deaf-Blind (NFADB)

141 Middle Neck Road
Sands Point, NY 11050
Phone (800) 255-0411, Fax (516) 883-9060
TTY (800) 255-0411
nfadb@aol.com
http://www.nfadb.org

NFADB is a national network of families who focus on issues surrounding deaf-blindness. NFADB advocates for all persons who are deaf-blind, supports national policy to benefit people who are deaf-blind, and encourages the founding and strengthening of family organizations in each state.

Training and Educational Resources Program Perkins School for the Blind

175 North Beacon Street
Watertown, MA 02472
Phone (617) 972-7519, Fax (617) 923-8076
betsy.mcginnity@perkins.org
http://www.perkins.org/

The Training and Educational Resources Program provides information, training, and educational resources to families and professionals throughout the nation. Emphasis is on families and professionals involved with children and youth who are blind, visually impaired, and deafblind, including those with additional disabilities.

U.S. Department Of Education, Office of Special Education Federal Deaf-Blind Programs (326C Grants)

Office of Special Education and Rehabilitation Services
Research to Practice Division
Elementary and Middle School
550 12th Street, SW - PCP-4086
Washington, DC 20202-2600

Attn: Anne Smith, Ed.D., Project Officer
Phone (202) 245-7529, Fax (202) 245-7617
anne.smith@ed.gov
http://www.ed.gov/about/offices/list/osers/osep

The Office of Special Education Programs supports projects to improve and enhance services that are provided by state and local education agencies to children and youth who are deaf-blind. This is done through a program of grant awards that address technical assistance, research, development, pre-service and in-service training, and parental involvement activities.

This article is available on the web at http://www.nationaldb.org/NCDBProducts.php

For additional resources on all aspects of deaf-blindness, see the Selected Topics section of the NCDB Website: http://www.nationaldb.org/ISSelectedTopics.php

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