

CHAPTER 2

Understanding Deafblindness

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In order to help



A PERSON WHO IS DEAFBLIND COMMUNICATE TO THE BEST OF HIS OR HER ABILITY, WE NEED TO UNDERSTAND DEAFBLINDNESS AND HOW IT AFFECTS COMMUNICATION. FIRST, WHAT EXACTLY IS DEAFBLINDNESS, AND WHO IS A DEAFBLIND PERSON?

ONE MIGHT INITIALLY SAY, WITH A LOT OF COMMON SENSE, THAT A PERSON WHO IS DEAFBLIND IS SOMEONE WHO CAN NEITHER SEE NOR HEAR. HOWEVER, AS ANYONE WHO HAS ENCOUNTERED EITHER DEAF OR BLIND PERSONS KNOWS, THERE ARE DEGREES OF DEAFNESS AND DEGREES OF BLINDNESS. THERE ARE PEOPLE WHO HAVE MORE OR LESS SEVERE VISION AND/OR HEARING IMPAIRMENTS AND DIFFERENT KINDS OF HEARING AND VISION LOSSES, AND THERE ARE MANY KINDS OF VISION AND HEARING IMPAIRMENTS. SO, THE QUESTION THEN BECOMES THE FOLLOWING: WHAT DEGREE AND KIND OF HEARING AND VISION IMPAIRMENTS, IN WHAT COMBINATION, CONSTITUTE WHAT WE WILL TERM “DEAFBLINDNESS”?

In this chapter, we will look at how deafblindness is defined, explore the diversity within the population of people whom we call deafblind, and explore the impact that this disability has on a person. Most importantly, we want to look at the unique nature of deafblindness as a disability and the effect it has on the individual’s ability to communicate.

Defining the Population

For our purposes, and for legal purposes, too, the definition of deafblindness is primarily an educational one. Here is the definition of deafblindness that appears in U.S. Federal law governing special education (Individuals with Disabilities Education Act [IDEA]):

The term, “children with deaf-blindness,” means children and youth having auditory and visual impairments, the combination of which creates such severe communication and other developmental and learning needs that they cannot be appropriately educated without special education and related services, beyond those that would be provided solely for children with hearing impairments, visual impairments, or severe disabilities, to address their educational needs due to these concurrent disabilities. (PL101-476, 20 USC, Chapter 33, Section 1422[2])

So, a person who is deafblind is one who cannot simply be thought of as a blind person with an additional disability (and therefore able to function without help in an environment geared toward helping people who are blind). A person who is deafblind also cannot simply be thought of as a person who is deaf and has an additional disability, but could easily be accommodated in a school program for children who are deaf. Even putting persons who are deafblind into the category of “severely or multiply disabled” will not, by itself, do justice to the nature of their disabilities and their needs. Why? That is a question that we hope to address throughout this chapter. We want to look at the unique nature of deafblindness as a disability and the effect it has upon an individual’s ability to communicate.

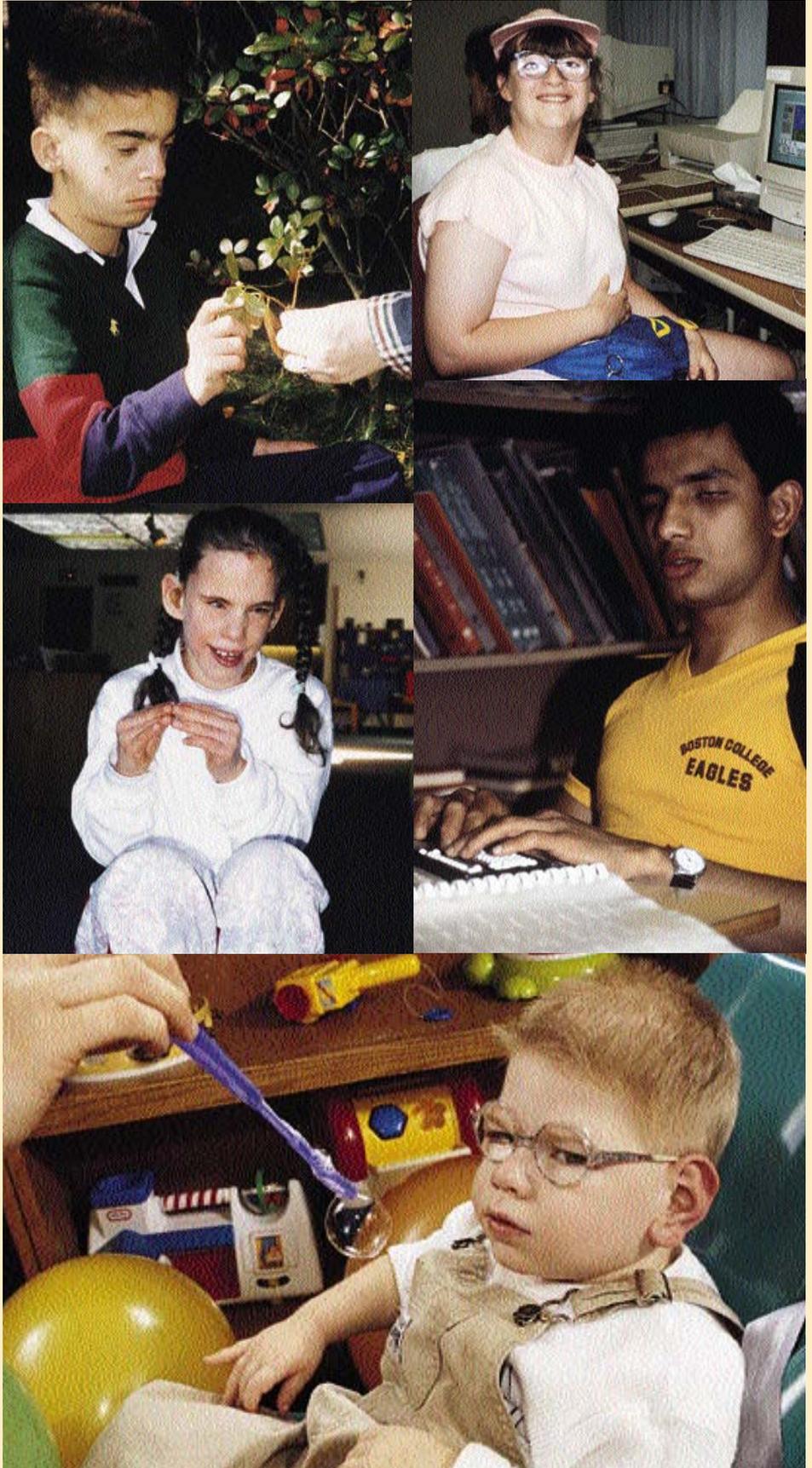
It is important to note here that throughout this book we will use the term “deafblindness” as a single word. In 1991, the International Association for the Education of the Deafblind (now known as Deafblind International) resolved to adopt this spelling rather than use the hyphenated term “deaf-blindness” to define the population of infants, children and adults we are talking about here. Although this change may not seem so significant, it demonstrates

that this is a unique disability, and not the sum total of a vision and a hearing loss.

We must also take note of the fact that the above U.S. definition of deafblindness is an extremely broad one. It includes, for example, the range of children and young adults described in these brief case descriptions:

- A three-year-old boy who is totally blind has a moderate-severe hearing loss, apparently normal motor and intellectual abilities, is just beginning to walk on his own, but has not yet learned any expressive language.
- A six-year-old with congenital rubella syndrome who is profoundly deaf, partially sighted, and has behavior disorders attributed to an attention deficit disorder. Intelligence estimates are that she is severely developmentally delayed.
- A 16-year-old girl with profound deafness, visual impairment, and severe cerebral palsy affecting all four limbs. Her intelligence cannot be accurately assessed because of lack of motoric functioning and absence of any consistent accessible language input during the course of her life. She has no apparent receptive or expressive language skills.
- A two-year-old girl who is medically fragile, born prematurely and suffering from prenatal brain hemorrhages, with profound deafness and total blindness, now cared for in a pediatric nursing home.
- A 20-year-old man who is congenitally deaf and adventitiously blind, with above average intelligence; presently educated for a half-day in a special setting for youth who are deaf-blind and for a second half-day in a mainstream situation in a

The current population of infants, children and adults who are deaf-blind is very diverse, although they all have common challenges caused by this disability.



boys' preparatory school where he attends classes with the help of a sign language interpreter. He plans to attend college.

These brief descriptions are a small sampling of the kinds of individuals who might rightfully be included in the category of those with deafblindness. From a sensory standpoint, the disability of deafblindness can be broadly divided into four categories:

- Those who are totally deaf and totally blind
- Those who are totally deaf and visually impaired
- Those who are hard of hearing and totally blind
- Those who have some use of residual hearing and vision

To further understand the individual with deafblindness, we must consider age of onset; any correction (i.e., surgery, lenses, hearing aids etc.); the extent of additional physical and cognitive disabilities; and additional health impairments. These are all factors that will affect the way we think about a child who is deafblind and that will help determine specific strategies we should use for instruction. Whatever specific sensory impairments and additional disabilities a child has, each one who is deafblind will require education by a teacher who has an appreciation of this unique disability. She can then build a relationship with the individual child that will maximize that individual's connection with other people and situations in the environment.

A Changing Population of Children

The population of children with deafblindness has widened considerably during recent years. In the United States, education of children who are deafblind began in earnest with the education of Laura Bridgman at Perkins School

for the Blind in 1837. Early programs for children who are deafblind were academically based and were usually associated with schools for the blind. They tended to serve children whose sole disability was deafblindness and who lost their sight or hearing after birth, rather than those who were born with this disability. The birth of about 5,000 children who were deafblind due to the rubella epidemic of 1964–1965 changed the nature of the education of children who are deafblind.

In 1968, the Federal government funded 10 regional centers for deafblind services around the United States. They were established to develop model programs and provide training to meet the needs of these children who were born with congenital rubella syndrome. This population had, relative to the current population of children, a defined set of medical characteristics (e.g., heart conditions, glaucoma, cataracts, sensory neural hearing losses). Although there was variation among individual children, there were many commonalities, especially regarding educational approaches that were effective.

The widening of the identified deafblind population since 1965 has occurred principally for two reasons. Advances in medical technology have resulted in saving the lives of children born prematurely and/or with multiple congenital anomalies; these children might, before this era, have died in infancy. Also, through improved medical diagnostics and advancements in the study of genetics, we are making strides in identifying children with low-prevalence genetic disorders. This means that many children are being served who previously would not have been identified as having vision and hearing impairments. Moreover, since there are now legislated mandates to serve all children with disabilities, there has been more effort to identify such

children and to provide high quality educational services.

Why a Categorical Definition?

Given that children and young adults who have combined vision and hearing losses have a wide range of needs, one might well ask, "Why is it useful to think of all under the one category of deafblindness?" Our experience, from our many years of teaching the whole range of children included in this educational term "deafblindness" is that it is, in fact, a very useful category for a number of reasons.

Communication: The Central Priority

When we define a child's disability as deafblindness, thereby placing the primary emphasis upon his sensory impairments, we then establish communication as the central educational priority. This is so because sight and hearing are the primary avenues of communication. We explained in the first chapter why we consider communication skills to be crucial in achieving the optimal quality of life for any individual. We believe that viewing a student from the perspective of deafblindness helps an educator to think most clearly and creatively about how to help him achieve his best communicative potential.

Need for Specific Educational Expertise

We hope to continually improve the body of knowledge and skills among teachers, families, caregivers, and other professionals and paraprofessionals; we are confident that this increased knowledge will help learners who are deafblind to achieve their maximum potential. In our efforts to do this, it is important that we have a strong understanding of just who is deafblind and what their needs are.

In order to train people to provide high quality services for the broad population of children and young adults who are deafblind, we need to know as much as possible about children and programs. There needs to be a defined field of deafblindness. Without a way of knowing who children are and where they are, and without having some knowledge about the educational practices that have been effective in educating them, teachers, children and family members remain isolated. They lack information and support necessary to meet the educational needs of the individual child for whom they are responsible.

In most developed countries, there is a trend now toward decentralization of special education services. Because of this trend, it has become increasingly difficult for teachers to collaborate with their peers who are teaching children with similar learning needs. Now, many teachers of children who are deafblind have never seen another child with this disability, nor have they talked with other teachers who are facing the same challenges. We need, therefore, to encourage the development of central resources that can develop expertise, provide support, and connect educators and families who have children who are deafblind. Emphasizing the uniqueness of deafblindness as a disability can help overcome their isolation. It is very helpful for teachers of children with deafblindness to have a familiarity with other persons who are deafblind, and with other teachers who are teaching students who are deafblind.

If you are teaching a child who is thought of as being “deafblind,” it will help you greatly in planning for that child and in envisioning how to teach her if you can visit and get to know a range of persons who are deafblind, such as those described above. If you have experience with this broad range

of persons with deafblindness, either through actual visits or through reading case studies (such as are included in this text), then you will have a more effective way of imagining how to teach the child who is deafblind and is in your charge. Comparing her solely with the severely impaired children you know will limit your ways of understanding her and of teaching her. (The same would be true if she were in a class of children who were blind or deaf and you thought of her primarily as blind, or deaf, and taught her from that perspective only.) Similarly, if you are able to connect with other teachers who are teaching children with deafblindness, you can share information and observations, and can thereby become a more effective teacher. Making such a connection can depend on thinking of



Laura Bridgman and Dr. Samuel Gridley Howe.

the child as having deafblindness as a primary disability.

The way we categorize in our minds affects the way we behave. Saying that a child is deafblind highlights her sensory impairments as primary and implicitly asks us

to think of her alongside others with dual sensory impairments (regardless of intelligence level, social status, physical impairments, etc.). Through this process of heightening our awareness of the impact of this disability, we hope not to segregate, but to relate to the person who is deafblind in a way that will enable him or her to participate more fully in society.

Challenges Shared by People Who Are Deafblind

Isolation: As we have said earlier, the senses of vision and hearing are called distance senses. These senses connect the person with the world that extends beyond his or her personal body space. It is through these senses that individuals who have sight and hearing learn most concepts about the world and develop social relationships.

A person who is deafblind cannot listen to or read the sign language of someone who is speaking or signing to him at a distance. She cannot passively observe what other people are doing, overhear conversations, or observe with clarity the environment around her. Because deafblindness severely limits the opportunity for a person to have contact with people and things in the environment, all people who are deafblind, regardless of their cognitive or physical capabilities, are reliant to some extent upon others to help them access, interpret, and organize information from the surrounding world. It is important to remember, as we think about our interactions with individuals who are deafblind, that they are essentially isolated unless they are in close proximity, or in direct physical contact, with another person.

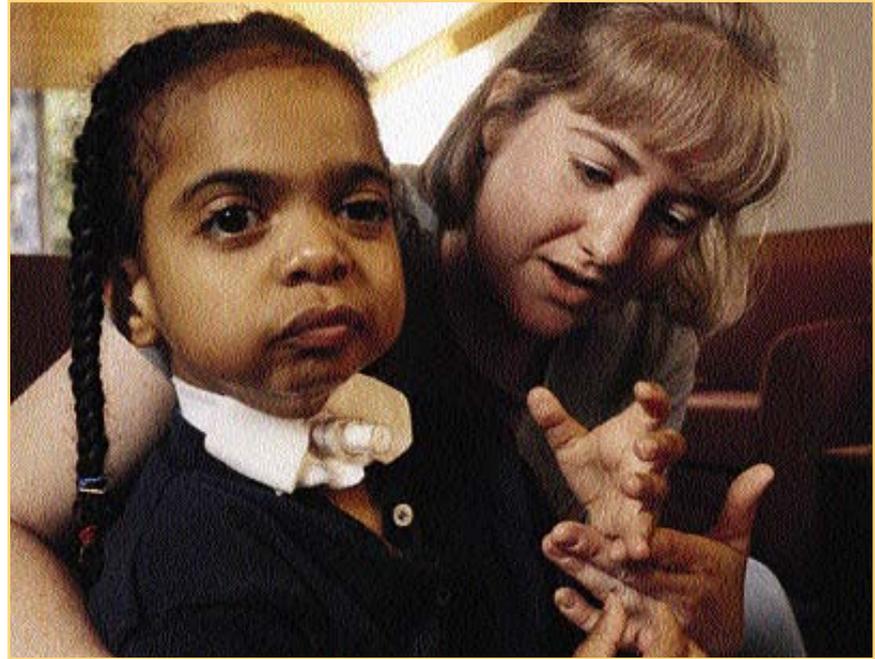
The sense of isolation caused by deafblindness creates the greatest barriers in the life of a person with this disability. It is important to note that this sense of isolation

does not occur only in the portion of the deafblind population who have no usable sight or hearing. For the person who is totally blind, and has some usable hearing, isolation begins as soon as the conversation stops. Or, when several people converse in a group, he may not be able to follow the rapid shifts in conversation from person to person and topic to topic. This “missing” of large pieces of what is being said isolates the individual from the group discussion. Once the person who is deafblind has lost the flow of a conversation, he is likely to become inhibited about participating for fear of saying something that is inappropriate or has already been said.

Persons with deafblindness have a number of additional characteristics in common that, while they are not necessarily obvious at first glance, reveal themselves as important considerations in teaching (Robbins, 1983). In addition to the communication difficulty highlighted above, we discuss below some experiences and needs generally shared by persons who are deafblind.

Need for Individual Instruction: Either touch or very close proximity is required in order to make contact meaningful for someone with both vision and hearing impairments.

Reliance Upon Interpreters: Usually a person who is deafblind needs to have the distant world interpreted for him so he may have access to it. This interpretation may happen in a number of different ways. It may include not only traditional interpreting of conversations but also descriptions of physical surroundings and context, as well as simplified descriptions of interactions. In any case, a close working relationship with an interpreter is shared by many people who are deafblind. This interpreting may be done by a



Many children who are deafblind have additional complex health challenges.

variety of people, depending upon the needs of the person and the situation. Not all people who are deafblind need a certified interpreter. This will depend on individual needs. But all people who are deafblind routinely need someone to connect them to people, events and places.

Limited Number and Variety of Experiences: Not being able to see and hear narrows one’s world, often so much so that it extends no further than the fingertips. If you think for a moment about how much information you receive everyday through your eyes and ears, you begin to sense what a person who is deafblind is missing. Multiply this by days, weeks, months, years, and you have an even clearer idea of the volume of missing information.

Limited Social Experiences: Usually a person who is deafblind cannot communicate with more than one person at a time. This means their social experiences are very different from those of hearing and sighted people, who are accustomed to being relatively at ease in a group, and who have a

broad experience of social customs and amenities. Lacking these experiences, a person who is deafblind, no matter how intelligent, may appear socially awkward or rude, when in fact he simply has not had the chance to participate in exchanges of facial expressions and gestures which are very important aspects of social interactions.

Multiple Hospitalizations: The majority of the current population of children who are deafblind have had prolonged hospitalizations for often life-threatening illnesses. These hospitalizations have frequently taken great emotional toll on these children and their families. They may be the source of anxieties that may seem groundless to an insensitive observer, but are actually rooted in a great deal of concrete experience.

The challenges listed above greatly affect the development of the whole person. In spite of these challenges, people who are deafblind have unique opportunities for intimacy and depth of experience that sighted-hearing people may lack. Educators must take into account these differences and consider how they may influ-

ence interactions with people who are deafblind.

Importance of Assessment

The population of infants, children and adults who are deafblind is now very diverse, and this diversity makes it important to recognize a child as deafblind as early as possible. We need to be certain we are recognizing the significant impact of the child's combined sensory losses on his or her development, and we must address the needs that these sensory losses create within the child's educational program.

In identifying children as deafblind, we are also highlighting the importance of sensory assessment as a crucial piece of the educational assessment process. Often, especially in the population of children with significant additional, very "visible" disabilities, it is easy to overlook the need to fully assess the child's vision and hearing. For, example, when a child has significant health and physical challenges, people will often say, "His vision and hearing are the least of his problems." When a child has severe cognitive delays, the assessment of vision and hearing will often become a low priority among people who are not knowledgeable about deafblindness. However, knowing as precisely as possible how a child receives information, and understanding the possibilities for treatment (e.g., assistive listening devices, glasses, corrective surgery) and intervention, can significantly expand the child's learning possibilities.

Impact of Sensory Losses on Attachment, Communication, and Concept Development

We have just defined deafblindness as it relates to a child's educational needs. We also need to think about what deafblindness means experientially and how it specifi-

cally affects communication. What does it feel like to have limited, or no, vision and hearing? What does this mean in terms of how one learns to communicate?

Throughout this book we will continue to talk about deafblindness as a unique disability; however, we also need to be knowledgeable about the impact of each sensory loss.

Blindness

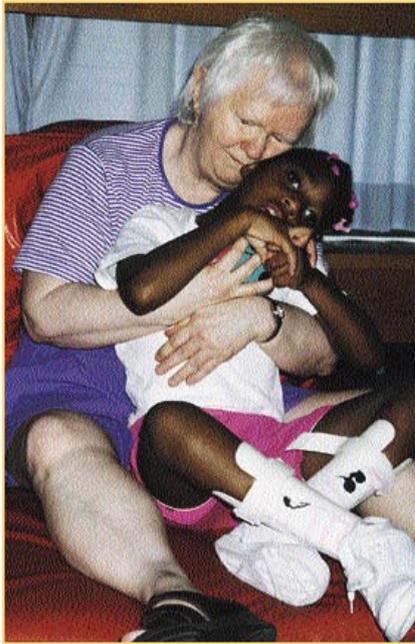
If a child is born totally blind, how will that limitation affect her connection with those around her? The literature estimates that 75%

of most people's learning comes through vision (Smith & Cote, 1982). This sounds very dramatic and may seem overstated, but this statistic rightfully highlights the great importance of a child's visual connection with the environment—with objects, people, actions, and relationships.

One of the most comprehensive and accessible works done on the effects of blindness on communication is by Selma Fraiberg, a psychiatrist who became interested in blindness in the 1960s, when she met a child who was blind and who presented unique difficulties.

It is important for teachers to know the educational practices that are effective in teaching children who are deafblind. Many children, for example, require tactile sign language for optimal understanding.





Children who are deafblind are isolated unless they are in close proximity or in direct physical contact with another person.

She has studied blind children extensively and her book, *Insights from the Blind*, provides a sensitive account of the development of communication skills in several blind children.

Bonding: Dr. Fraiberg carefully observed the interactions between infants who were blind and their mothers, and tried to understand what those interactions felt like from both points of view—the baby’s and the mother’s. One of the first things she noticed was that often an “estrangement of mother and child began in the early months” (Fraiberg, p. 60). This seemed to happen because the blindness of the baby, for the mother, “feels curiously like a rebuff if you do not know that the baby is blind.” A sighted infant’s smiles provide a great deal of reinforcement for a new mother, and they are in turn reinforced for the baby by the mother’s return smiles. When this smile dialogue is interrupted because a baby cannot see well, or at all, the mother may become depressed, especially if there has been no diagnosis of

visual problems (which would serve to explain to her the child’s lack of smiling). She may withdraw from her infant.

Dr. Fraiberg found that most mothers of babies who were blind needed to be taught not to look for responsiveness and initiative in their children’s faces, but to look instead at their body language, especially at their hands. She points out that this is not natural for us because we are so conditioned both to look at another’s face for responsiveness and to express ourselves through our own faces. In fact, for a sighted infant, the eyes are a main way of initiating social exchange. A baby, through her eyes, expresses attention, longing, doubt, boredom, questioning. Fraiberg found that when the mothers of blind babies were taught to look at their children’s hands rather than their faces for these signs of attention, excitement, exploration, and anticipation, they were richly rewarded by discovering that the babies were, in fact, expressing a wide range of feelings and interests—emotions that were not evident on the children’s faces. Once the mothers could see this, Dr. Fraiberg discovered, a more satisfying dialogue could resume between infant and parents. “Even grief [over the diagnosis of blindness] could be managed when the baby brought his own rewards in response, in diversity of social exchange, and in becoming an active partner in the love relationship” (p. 108). When such help was not available, and when the dialogue was not well established between mother and baby, Fraiberg found that there often ensued social and emotional difficulties for the children who were blind, who were not able by themselves to discover adequate ways of relating socially without the initial experience of adequate relations with their mothers.

Establishing Object Permanence:

For an infant who is blind and who is only a few months old, an object does not exist if he is not touching it. Even toys in the baby’s crib might as well not exist if he doesn’t accidentally put his hand on them or roll over onto them. The sighted infant learns about the existence of objects apart from himself by learning to synthesize information from his eyes, his hands, and his mouth. The play that sighted babies do in front of their faces—at first accidentally, and later intentionally—with their mouths, their hands, their fingers, and with toys, teaches them that what they see has substantiality. Through repeated experimentation, practiced for hours at a time, they learn that certain movements create certain visual results, and that certain visual stimuli have certain physical feelings associated with them. Gradually, through trial and error, they are able to reach for and grasp something they see with their eyes. They have come to trust the information from their eyes that tells them the object they are not yet touching has substantiality, and, if reached for, will reward their open hands with texture and weight. They have come to believe this information so surely that they trust that even if the object is covered with a cloth, or dropped on the floor out of sight, it still exists. This is what we call object permanence.

Dr. Fraiberg found that children who were blind had a harder time than sighted children in establishing object permanence. That is, they could not as easily hold the image of an object in their minds when the object was not physically present. The ability to do so is intimately related to the ability to name and categorize objects, and thus is clearly tied to language and conceptual development.

Blind children, deprived of the visual connection with objects to

one degree or another, must learn other, less direct ways of communicating with the object-world or learning about it—trusting its very existence apart from their physical connection with it. For a child who is blind and can hear, the ear and sound begin to substitute for the eye and sight. Clapping games, toys that make noise, the hand on father's speaking mouth, the accidental and later intentional brush against a hanging bell—these are the experiences that teach “ear-hand coordination” and the beginning of a sense of object permanence. Given enough auditory stimulus in place of visual stimulus (and Fraiberg found that this process could be greatly facilitated through the parents' sensitive provision of these experiences), the child who is blind will come to trust that mother's voice means that mother is near, that a bell sound indicates the existence of a round metal object, that a lullaby sound tells that a favorite wind-up teddy bear is near, even if the hands are not able at once to contact these things.

One begins here to get a sense of the monumental task ahead of the infant who is both profoundly deaf and totally blind. Right here, at this most basic juncture of development where the baby must come to know that objects exist apart from him or herself, the baby who is deafblind has a very hard task that will require much help and patience. Likewise, his family will need a great deal of information and support to build these early relationships.

Children who are blind and do not receive help in establishing object permanence will lag behind in language development because the ability to name objects depends upon some sense of their existence apart from oneself. With help, this naming facility will happen in due course, not far behind a normally sighted child's ability.

MOTHERS OF BABIES WHO ARE BLIND NEED TO BE TAUGHT TO LOOK FOR RESPONSIVENESS IN THEIR BABIES' BODY LANGUAGE, ESPECIALLY THEIR HANDS.

Mobility: Another lag will happen too, if the child who is blind is not helped to achieve object permanence. This child may be slow to develop mobility and may therefore have additional cognitive and communicative delays. Moving around in the world and exploring are ways in which a child comes to know about her world, develops curiosity, and learns about the ways in which people and objects are related to one another. Mobility develops in large part, in a sighted infant, as a result of vision. Visual objects are “lures” for the child—they draw her out into the world. She learns to crawl by attempting to reach something she can see but cannot yet touch. She learns to walk as her visual world draws her upward. As she learns these skills, she becomes more of a conversationalist, asking questions, protesting, requesting things. Her communication skills develop as she moves about in the world more and more.

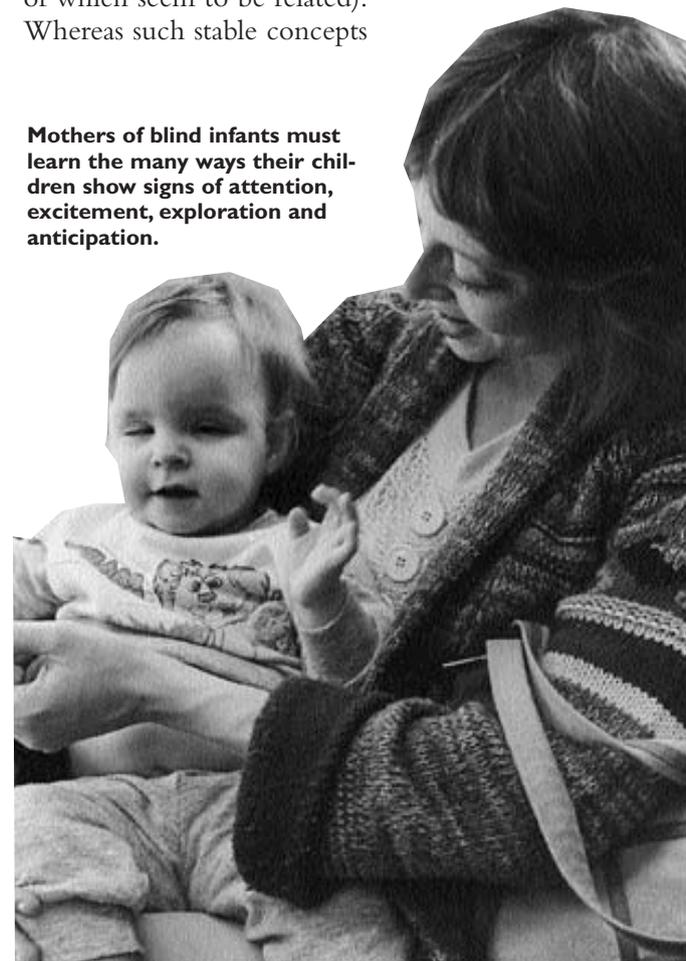
The child with sight and hearing is motivated to crawl toward the brightly colored toy across the room or toward Grandma's outstretched arms and encouraging words. Without visual lures, or the sound lures that emerge with object permanence, a child who is blind will not be motivated to move forward. Dr. Fraiberg found that it was not mobility training per se that helped children who are blind to learn to crawl and

walk, but it was “educational work in the areas of human attachment and prehension (reaching and grasping)” (p. 278). She observed that an educational program that provided training for the parents in bonding with their children and in helping their children learn about reaching “can confidently wait for the baby to ‘invent’ mobility for himself” (p. 278). Then, cognitive and communication gains will follow naturally as the child begins to explore his world.

Use of Personal Pronouns, Self-Concept and Time Concept:

Dr. Fraiberg observed that children who are blind experienced difficulty in one other area of communication development. She recounts the story of “Kathie,” a very bright child who was blind and who, in spite of her intelligence and rich language environment, experienced delays in her ability to use personal pronouns appropriately, in her development of a stable self-concept, and in her development of time concepts (all of which seem to be related). Whereas such stable concepts

Mothers of blind infants must learn the many ways their children show signs of attention, excitement, exploration and anticipation.





Children with significant vision loss have more difficulty holding the image of an object which is not physically present than do children who have vision.

are usually achieved by most sighted children at somewhere around three years of age, Kathie did not achieve them until four years and 10 months. According to Fraiberg, the observation of Kathie taught her that “the acquisition of personal pronouns goes beyond practice with grammatical tools. It goes beyond the influence of the language environment. [It reflects the] extraordinary problems in constructing a self-image in the absence of vision” (p. 268).

During the time from about two-and-a-half to three years, when Dr. Fraiberg was observing Kathie with a view toward understanding these aspects of her language development, she observed that Kathie “could not represent herself through a doll or a toy... She could not recreate or invent a situation in play. She could not attend to a story or answer questions regarding a story or tell a story herself. She could not spontaneously report an experience” (p. 256). In other words, she could not yet “see herself as an object to others” (p. 260). Vision is an important aid to a sighted child in developing a self-concept. Such experiences as seeing one’s own hands, seeing one’s image in a mir-

ror, comparing visually one’s own body with others’ bodies, all contribute to a young child’s concept of himself. A child who is blind and who does not have these experiences will have delays in forming this self-image. In fact, some children who are blind who have not had any help may be extraordinarily late in being able to accurately use “I” and “you,” and in being able to recount stories of their past experiences. Such communicative delays may look like autistic behavior, but may actually have their basis in the lack of visual experience.

Development of Abstract

Concepts: Finally, we must mention the effect that limited or absent vision is likely to have upon conceptual development and, as a result, upon communication. A child who is blind gains knowledge of the world through her remaining senses: hearing, touch, taste, smell, and kinesthetic experience. Some objects and ideas are particularly difficult to experience through these senses alone. How, for example, would one explain what a cloud is to a child who is blind? She cannot see it, hear it, touch it, taste it, or smell it. What

about a sunset, a rainbow, stars? The absence of the experience of such things is only really a deficiency when viewed from the unreflective point of view of those of us who are sighted. If we are sighted people communicating with persons who are blind, we must be careful not to assume that their experiences match ours in all areas; we must remember, as we speak, to put ourselves in their shoes. We must not assume that lack of knowledge of some things we take for granted means that they are unintelligent or that communication is therefore impossible. It may actually be a richer communication if we each take the time to make sure we are understanding one another.

The person who is sighted, from the point of view of the person who is blind, may actually be “deficient” in other senses. Sight usually provides a great percentage of the information that we receive about the world. Without that focus, or dependence on vision for connection, the other senses may become sharpened. Jacques Lusseyran, a Frenchman who became blind, has described some of his experiences of heightened sensitivity.

As soon as my hands came to life they put me in a world where everything was an exchange of pressures. These pressures gathered together in shapes, and each one of the shapes had meaning. As a child I spent hours leaning against objects and letting them lean against me. Any blind person can tell you that this gesture, this exchange, gives him a satisfaction too deep for words.

Touching the tomatoes in the garden, and really touching them, touching the walls of the house, the materials of the curtains or a clod of earth is surely seeing them as fully as eyes can see. But it is more than seeing them, it is tuning in on them and allowing the current they hold to connect with one’s

own, like electricity. To put it differently, this means an end of living in front of things and a beginning of living with them. Never mind if the word sounds shocking, for this is love.

You cannot keep your hands from loving what they have really felt. (Lusseyran, pp. 27-28.)

Deafness

We have seen at least some of the effects that blindness by itself is likely to have upon a person's connection and communication with the world. What about deafness or hearing impairment? How might an inability to hear affect how a person connects with those around him or her?

Feelings of Powerlessness in

Mother: A deaf infant with normal vision will not have the same trouble developing early bonds with his caregivers as an infant who is blind because, as we have seen, the eyes are a main avenue for these early bonds. Smiles can easily be exchanged and body language can communicate affection and connection when a child is hearing impaired and has intact vision. It can happen, though, that an early diagnosis or suspicion of deafness may instill in the mother of a baby who is deaf feelings of powerlessness and/or depression that may affect her rapport with her child. Hilde Schlessinger, who has done significant longitudinal studies of children who are deaf and their caregivers, has found that the most typical effect that these feelings of powerlessness are likely to have is to cause the mothers to become "over-directive" in their attempts to communicate with their children; that is, their communication with their children more resembles a monologue than a dialogue. They take more turns than their children, and most of these turns are commands, requests and directive questions. This over-directiveness may have the effect on the infant of causing him to be

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less communicative, less spontaneous, and less socially adept. These inhibitions may affect his later language development because language skills grow out of active engagement with the world, and they do not flourish when a child is a passive reactor to an overdirective environment. Schlessinger found that when mothers could be helped to feel less anxious and more powerful, they helped their children who were deaf to be better, more spontaneous communicators.

Language Development in a Hearing/Speaking Environment:

Deafness most significantly affects communication in the development of language. People need to have language input in order to learn language. Without accommodation, a child who is deaf in a hearing world does not have access to enough language to significantly activate her own innate capacities to develop language. The innate capacities for language seem to be most flexible and active during the early years of life. If a child does not receive language stimulation when young, she is at particular risk. A child thus deprived may never be able to be fluent in any language.

Hearing persons receive most of their language input through their ears. Before

a child can say his first words, he has heard thousands of words and sentences thousands of times, and has somehow begun to make sense out of them. A child without hearing or with severely impaired hearing does not have access to language input unless it is provided to him through special means. Even certain kinds of relatively moderate hearing losses that allow a person to hear at speech levels can greatly restrict the useful linguistic information a child receives from his environment because many significant sounds are obliterated.

A child who is deaf or severely hearing impaired and who grows up in a hearing world is at a distinct disadvantage for learning language. Her eyes must serve as the sole receptors not only of words, but of sentences, intonation patterns, and emphasis; they must also take over the "antenna-like" function that the ears serve for hearing people—scanning the environment on all sides, picking up indications of movements that would tell of danger or pique interest (Myklebust, 1960). Obviously, the eyes alone will miss many of these things. Lipreading, even at its best, is a very inefficient way to receive

A child who is deaf must be continually exposed to language in a form that is accessible to her.



language. Estimates are that an intelligent speech-reader, with good visual access to the speaker's face, and with good contextual clues, understands with certainty only about 30–40% of the words spoken to her. Given this fact, one can begin to imagine the limitations that a person who is deaf must live with when spoken language is her only method of communication. If visual impairment and/or any other impairments are added to the deafness, the communicative isolation becomes profound indeed!

Consider, too, the fact that much of what hearing people learn in life is “overheard.” (Ears are like antennae, in many ways.) In a household, at school, at a store, in a theater—in all of these places and others, a hearing child overhears hundreds and hundreds of exchanges between adults, between other children, between adults and children. People around him discuss all manner of things, exchange information, struggle aloud with decision making, resolve emotional difficulties, and engage in social amenities. All of this the hearing child absorbs and makes some sense of; some of these exchanges he later uses as models for his own behavior and communicative exchanges. This “overheard” experience is a crucial part of his socialization and an important source of his information about the world.

What about the child who is profoundly deaf in a hearing/speaking environment? The simple fact is that virtually all of these forms of incidental learning are unavailable to him. The communication he receives is only that which is directed exclusively toward him, and even that he may receive with difficulty. Think for a minute about what this might mean in terms of the development of his communicative competence. Not only is the information he possesses about the world likely to



be far narrower in scope than that of a hearing child, but, perhaps more importantly, his models for how to interact socially, how to resolve difficulties, and how to cooperate in decision making will be either severely restricted or nonexistent unless special provisions are made.

Language Development in a Signing Environment: We have been speaking about the deaf child in a hearing/speaking environment. The same difficulties do not exist in the same way for the deaf child in a signing environment. If you can imagine a deaf child whose parents and siblings routinely use sign language as a medium

of communication, you can envision all of the normal social interactions occurring in a way in which the deaf child can access them. He can visually “overhear” his parents discussing things, for example, or struggling with a decision, or exchanging information. And he can learn a great deal from these exchanges, all of which help him engage in similar exchanges himself at a later date. With visual access to language, he becomes part of a social network in which he can participate as an equal member.

Research shows that children who are deaf and have deaf parents, and who are raised in an environment where sign language



Opportunities for experiential learning are critical in order for children who are deafblind to learn concepts about the world around them.

is the primary medium of communication, do not have trouble learning language in the ways that children who are deaf and have nonsigning parents do. In fact, children who are deaf and who are exposed to sign language from birth “babble” with their hands (experiment with the hand shapes used to form the signs of sign language) at the same age their hearing peers babble with their voices (or, in some cases, earlier). They also produce their first recognizable signed words at the same age as hearing counterparts produce spoken words. They also make two- and three-word sentences earlier than peers who are hearing (Caselli and Volterra, 1994). Children who

are deaf and have signing parents who are deaf also tend to fare better socially later on, probably because of their increased self-esteem, ease with communication, and the availability of appropriate role models for them.

Feelings of Isolation: Envisioning these very different scenarios—the deaf child in a hearing/speaking environment, and the deaf child in a signing environment—makes us realize the truth of this statement made by Hilde Schlesinger:

Profound childhood deafness is more than a medical diagnosis: it is a cultural phenomenon in which social, emotional,

linguistic, and intellectual patterns and problems are inextricably bound together. (Schlesinger & Meadow, 1972, p. 1)

To think of deafness only as an impediment to learning language is to think far too narrowly. Deafness, especially when it exists largely or wholly within a hearing/speaking cultural environment, has much wider and more profound implications. It isolates to a far greater degree than may be evident at first glance. In fact, as a single disability, it is deceptively invisible. A deaf person may be quietly present with a group of hearing/speaking persons, may be visually alert and appear to be functioning normally, and yet may be profoundly isolated. It is a challenge for hearing people to understand and empathize with the extent and quality of that isolation, and further, to understand their own complicity in that isolation. A person with a physical

disability, or one who is blind, may immediately invite creative responses to their isolation. Deafness is not so obvious; it does not present itself as being a difficulty in the same way, and so it is likely to be ignored. What is more, it demands of us that we learn to communicate in a whole new way. It presents us with this challenge of learning to speak with our hands and faces and bodies, as well as with our voices.

Helen Keller, commenting about the comparative effects of her deafness and blindness, spoke of deafness as being the more difficult of the disabilities:

I am just as deaf as I am blind. The problems of deafness are deeper and more complex, if not more important, than those of blindness. Deafness is a much worse misfortune. For it means the loss of the most vital stimulus—the sound of the voice that brings language, sets thoughts astir and keeps us in the intellectual company of man. ...If I could live again I should do much more than I have for the deaf. I have found deafness to be a much greater handicap than blindness (from a letter to Dr. J. Kerr Love, March 31, 1910, reprinted in the souvenir program commemorating Helen Keller's visit to Queensland Adult Deaf and Dumb Mission in 1948). (Ackerman, 1990, pp. 191-2)

Deafblindness

What, now, of deafblindness? What does it mean to be like Helen Keller, and to be missing significant amounts of both hearing and vision? It is safe to assume, at the outset, that deafblindness

includes all of the difficulties of both deafness and blindness. However, when both distance senses are absent, or greatly limited, the difficulties are not simply doubled, they create a unique disability unto itself.

Isolation: Since vision and hearing are our two distance senses, the absence of one places a great emphasis on the remaining distance sense. A blind person normally compensates with acute hearing; a deaf person is often extraordinarily visually alert and gains access to language, when possible, through her eyes.

A person who is deafblind has limited opportunities to compensate. Increasing emphasis falls upon the near senses, especially touch, and upon whatever remains of vision and/or hearing. The world of the person who is deafblind shrinks. For many it does not go beyond the reach of the fingertips. For others it extends only slightly farther than that. Robert Smithdas, a man who is deafblind, said:

For a deafblind person, the world literally shrinks in size and scope, and whatever knowledge is obtained must come through the secondary senses of taste, touch, and smell, and the exercise of personal curiosity and initiative. Consequently, a deafblind person matures more slowly than is considered normally acceptable, and the individual will be prone to greater frustrations in expressing wants and needs.

Blindness takes an individual away from things, and deafness takes him away from people.... Deafblindness creates unique problems of communication, mobility, and orientation peculiarly its own. (Robbins, 1983, p.3-3)

A person who is deafblind is isolated both from people and from things. Lewis Hoskins, another man who is deafblind, described this feeling of isolation like this:

I can only talk with one person at a time, and only if that person is within

my reach. If I am in a crowded room, and no one is within three feet of me, I might as well be in a closet. It is very easy for me to misunderstand, so communication is often very slow. (Robbins, 1983, p.3-3)

That isolation becomes even more profound if the people who are physically near to the person who is deafblind are not equipped—either emotionally or technically—to communicate with him. Suppose the person who is deafblind reaches out to touch, but the one whom he touches knows no sign language, or is frightened of blindness, or is too pitying to be able to converse? In any of these, or a number of other imagined instances, the person who is deafblind may touch with his fingers, but not be able to communicate in any significant way. So, the hurdles are enormous.

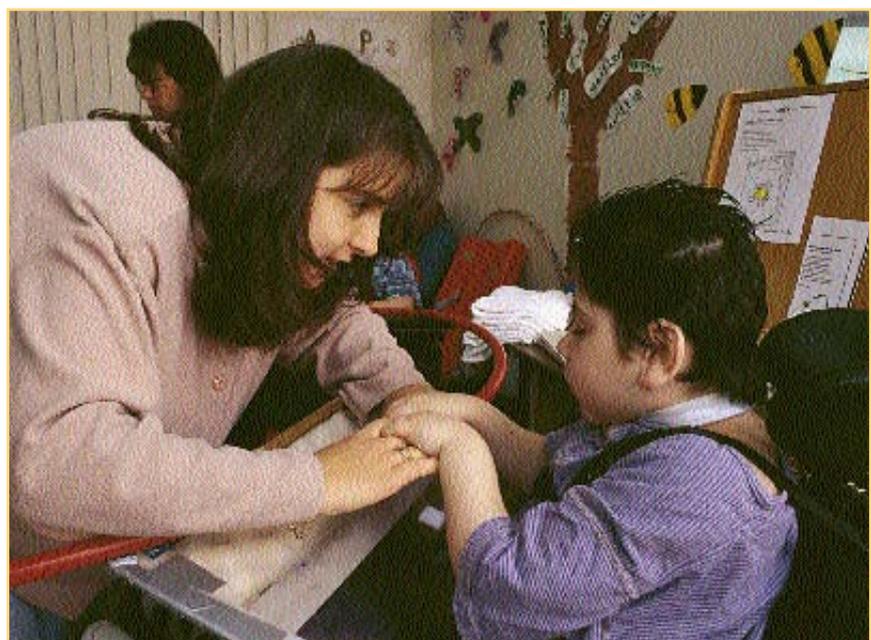
Isolation imposed by lack of vision and hearing presents its most formidable challenges when both of these senses are absent from birth. Bonding with the mother or early caregivers forms the basis for all further gains in communication. Without vision or hearing, such bonding is very diffi-

cult, although certainly not impossible to achieve. In addition, as we saw in our discussion of blindness, the achievement both of a sense of object permanence and of a stable self-concept or body image is very hard for the child with blindness; with the additional absence of hearing, or impairment of hearing, the task becomes monumental.

People who are deafblind, who lost one or both of their distance senses after they had already bonded with their mother and attained a stable self-concept, generally fare much better than those who must be helped through these stages with only their senses of touch, taste and smell to compensate. The baby born both deaf and blind has an experience of the world that is so qualitatively different from our own that the bridging of the gap between us and this child presents a rare challenge.

Presence of Additional Disabilities: Another very significant reason why we cannot think of deafblindness as simply the sum of deafness and blindness is that when a person is missing both hearing and vision, it is highly likely, though not necessarily the

Children who are deafblind and have additional disabilities challenge us to develop creative strategies for developing meaningful communication.

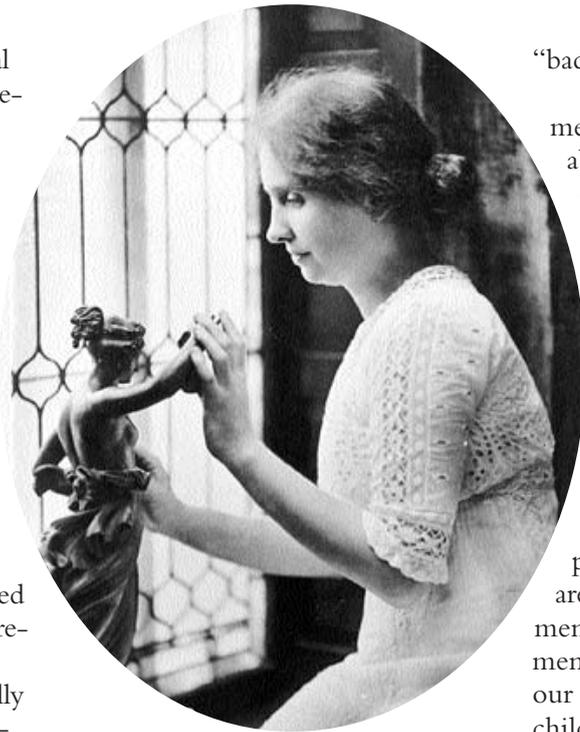


case, that there will be additional medical and neurological involvement that will affect his or her overall developmental growth. This becomes more true as advances in medicine result in the saving of lives of children born with multiple congenital anomalies and with rare genetic syndromes. In such cases, the challenge to communicate with these children is intensified: Caregivers and educators must be able to imagine the experience of one who not only cannot see or hear, but who may be also limited physically (as, for instance, in cerebral palsy), mentally (as in brain injury of various kinds), medically (as with the infant who has malfunctioning organ systems and requires significant hospitalizations), and/or emotionally (as the result of any or all of these other difficulties). Only by being able to imagine their experience can we communicate effectively with these children and help them communicate with us.

The presence of additional disabilities in a child who is deafblind creates challenges to our ability to assess children and to be creative in developing a system of communication that will meet his needs. Usually, a single, standard method of communication will not meet the needs of children who are deafblind and have additional disabilities. Such children challenge us to learn as much as we can about the avenues through which a child can receive information. We need to know how well a child can process information and how he expresses his thoughts. We must turn this understanding into creative strategies for developing meaningful ways to communicate.

Importance of Diagnosis and Assessment

Our discussion of diagnosis and assessment will occupy a chapter



Helen Keller

all its own. For now, we need only say that we need to have as clear an idea as possible of what a child hears and what she sees. This essential information will enable us to imagine with as much accuracy as possible her experience of the world, so that we may thereby connect with her and help her to connect with the world around her. The importance of these assessments is often underestimated, especially when a child with multiple disabilities is concerned. Indeed, the use of clinical assessment, combined with specialized functional assessment, is essential in the process of enabling the student with deafblindness to join families, friends and environment.

The issue of clinical assessment of hearing and vision in many cases becomes quite emotional. The families of children who have undergone more invasive medical treatment during the first year of life than most of us will experience in a lifetime are often reluctant to submit their child to yet another procedure—one that is often viewed as unnecessary, also one that will often result in more

“bad news” or another label!

Thanks to the advances in medical technology, we are now able to much more objectively evaluate children’s vision and hearing than we were before. This can be achieved through such tests as Visual Evoked Potential (VEP), Auditory Brainstem Response (ABR), and otoacoustic emissions. Although results of these tests should not be considered definitive, they do provide valuable pieces of information that are essential to the total assessment process. Functional assessments should always be a part of our ongoing relationships with children.

Medical assessment is also a very important component of the diagnosis and assessment process. Many medical treatments exist that can result in a dramatic improvement in seeing and hearing. These can range from the prescription of medication to remove middle ear fluid to the surgical treatment of glaucoma. Because so many children who are deafblind have other multiple disabilities in addition to vision and hearing impairments, we must take every opportunity to ensure that we are maximizing the use of every avenue for learning and preserving whatever residual senses exist.

Cultural Attitudes Toward Deafblindness

Communication, as we have said, is a two-way process. Difficulties that people who are deafblind experience in connecting with the world lie not only with their own given limitations, but also in the world, or worlds, to which they are trying to relate. For most hearing and sighted people, deafblindness is an unimaginable condition, if only because of their lack of experience with people who cannot see or hear. It is, moreover, a frightening

condition because most of us depend so much on our vision and hearing. Trying to imagine being without one or the other can produce anxiety. We may not be wholly aware of such anxiety; it may manifest itself subtly. We may become silent as we pass a blind person on the street or in a hallway. We may stare curiously and furtively at a group of deaf persons conversing in sign language. We may feel helpless in the presence of someone who can neither see nor hear. Becoming aware of our own anxieties may help us overcome them, or at any rate will keep us from becoming victims of our anxieties. We may be able to make contact with a person who is deafblind, even as we begin to contact our own fears of isolation, or perhaps because we have contacted these fears and can therefore empathize.

These fears regarding deafblindness appear not only among sighted and hearing people; they appear also, and often more intensely, among the very groups one might expect would be most welcoming to people who are deafblind—sighted deaf people and hearing blind people. As Robert Smithdas says, “For most

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blind people, deafness is the worst thing that could happen; and for deaf people, blindness is equally frightening” (Robbins, 1983, p.3-3). As a result, a person who is deafblind among peers who are deaf or blind may find herself just as isolated as if she were among sighted and hearing people. This isolation, particularly among people who are blind, may be due not only to fears of deafblindness, but also to the simple fact that a common language mode is absent. A person who is deafblind who depends upon manual communication will not be able to understand the speech of a blind person, and vice-versa.

Many other overt and subtle cultural attitudes may come into play where people who are deaf-

blind are concerned. Over the world, people of various religions and ethnic groups have a wide variety of beliefs and attitudes concerning blindness and deafness, ranging from thinking of these handicaps as punishments for sins in past lives, to viewing them as signs of special recognition by God or gods, to feeling extreme pity or compassion for those who cannot see or hear. We will relate more easily to people who are deafblind if we can become aware of our own attitudes.

We might do well, as we examine our attitudes, to look not only at our culture as a whole, but to look also at the attitudes that are prevalent in our immediate group of friends and family. How do our friends feel about disabilities? Will I be ridiculed, or admired, or ignored if I choose to relate equally to a person who is deafblind? If I bring home a friend who is deafblind, what will be my family’s reaction? How do I know? How am I influenced, even subtly, by the anticipation or imagination of such reactions?

And, finally, we will also do well to remember that cultural attitudes, including our own, are always changing, even if sometimes slowly. We each play a part, through our actions and speech, in facilitating that change. Our own openness to persons with deafblindness, in small or large ways, will help influence society as a whole to be more receptive to those who cannot see or hear, and will thereby help them become less isolated. This openness will also help us all learn more about each others’ unique experience of the world.

This chapter has presented an overview of the unique disability of deafblindness. Although those who have this disability are each very different, each is also linked in innumerable ways to the others; each has, to some extent, experienced overwhelming isolation.

As society as a whole becomes more receptive to those who cannot see or hear, we will all learn more about one another’s unique experience of the world.



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