



Deafblindness

Barbara Miles & Marianne Riggio

[Excerpted with permission from Remarkable Conversations: A Guide to Developing Meaningful Communication With Children and Young Adults Who Are Deafblind (pp. 33-35). Perkins School for the Blind, 1999.]

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.33)

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.33)

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 difficult, 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

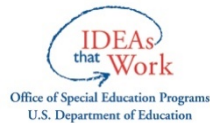
Another very significant reason why we cannot think of deafblindness as simply the sum of deafness and blindness is that when a person is missing both hearing and vision, it is highly likely, though not necessarily the case, that there will be additional medical and neurological involvement that will 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.

REFERENCES

Robbins, N. (Ed.). (1983). *Deafblind education: Developing individually appropriate communication and language environments*. Watertown, MA: Perkins School for the Blind.



The contents of this document were developed under a grant from the U.S. Department of Education, #H326T180026. However, those contents do not necessarily represent the policy of the U.S. Department of Education, and you should not assume endorsement by the Federal Government. Project Officer, Susan Weigert.