DEAFBLINDNESS

The term *deafblindness* describes a disability in which an individual has both a hearing impairment and a visual impairment. Deaf-blind individuals form a highly heterogeneous group that tends to have varying degrees of hearing and visual impairments. Deaf-blind individuals tend to prefer being referred to as "Deafblind," "Deaf-Blind," "Deaf-blind," "deaf-blind," or "deafblind." As with other disability classifications, deafblindness can be viewed from two opposing perspectives: the medical model and the cultural or social model. The terms *deafblindness* or *deaf-blindness* tend to emphasize the medical condition of the disability, whereas the terms *Deafblindness*, *Deaf-Blindness*, or *Deaf-blindness* tend to focus on the cultural membership of the individuals with the disability. The labels *deaf/blind* and *individuals with a dual sensory impairment* should be avoided because they are ambiguous. The term *deaf/blind* is ambiguous because it seems to refer to deafness or blindness instead of the combination of both impairments. The term *dual sensory impairment* leaves open to interpretation which two senses are actually impaired.

An individual is diagnosed with a hearing impairment if the individual has a hearing loss greater than 30 db in the better ear. There are different types of hearing loss. A conductive hearing loss consists of damage to or obstruction of the outer or middle ear. A sensorineural hearing loss is caused by damage to the inner ear or the auditory nerve. A mixed hearing loss is diagnosed when an individual has both a conductive and a sensorineural hearing loss. Cortical deafness is caused by damage to the auditory cortex of the brain. A hearing loss of any kind can range from mild to profound. A conductive hearing loss can often be aided with hearing aids and/or surgery. A conductive and a cortical hearing loss often cannot be improved by hearing aids or surgery because of the nerve damage, which causes distortions of sound.

A visual impairment is commonly defined as poorer than 20/70 visual acuity after correction or a restricted visual range of 45 degrees or less in the better eye. A visual impairment can be caused by damage to the eye itself, damage to the visual nerve, or damage to the visual cortex.

The causes of deafblindness vary greatly among the population of deaf-blind individuals. The potential causes of deafblindness include genetic syndromes (e.g., Usher's syndrome, CHARGE Association,

Goldenhar syndrome), illnesses or diseases of the mother or child (e.g., rubella, meningitis, cytomegalovirus, and tumors), or accidents (e.g., head injury). A combination of any of the above causes is also possible (e.g., an individual is born deaf due to a genetic syndrome and later loses her vision due to an accident or illness). The most common genetic syndrome causing deafblindness is Usher's syndrome and the most common disease to cause deafblindness is rubella. Depending on the underlying cause of deafblindness, the type of hearing and vision loss is also likely to vary. For example, individuals who experience a vision and a hearing loss secondary to Goldenhar syndrome are most likely to have a conductive hearing loss and damage to the eyes due to differences of the structure of the skull, whereas individuals who had meningitis tend to have a sensorineural hearing loss and a vision loss due to damage to the visual nerve.

Deafblindness must definitely also be viewed from a cultural perspective. Similarly to the medical background of deaf-blind individuals, deaf-blind individuals' cultural identity varies greatly. Depending on the age at which individuals became deaf and blind, they are more likely to associate and feel close to others most similar to themselves. This similarity is often based on the preferred method of communication used within the different groups. Individuals involved in the blind community and the mainstream community are likely to use spoken language as their main means of communication, whereas individuals involved with the Deaf community are likely to communicate by using a signed language. The Deaf-blind community is the community with the most diverse communication methods. Some may use a signed language, while others may use a spoken language; others may use writing, Braille, Tadoma (i.e., tactile speechreading), while still others may use a combination of all of these.

For a number of decades, research on the Deaf community has yielded a wealth of knowledge about Deaf culture as a minority culture. Deaf individuals tend to view themselves as members of a linguistic minority within American society and often do not view themselves as disabled. Members of the Deaf community tend to have a number of characteristics in common: They share a physical attribute (i.e., their deafness) and tend to identify as members of the Deaf community. Most Deaf individuals are very proud of their language (e.g., American Sign Language), which is commonly used in poetry and art. Deaf individuals also display a number of culturally characteristic behaviors. The most pronounced are possibly the attention-getting behaviors, which include stomping feet, waving arms across a large room, tapping on the shoulder, or even flashing lights. Deaf individuals tend to marry other Deaf individuals. Similarly to members of other minority groups, Deaf individuals often experience oppression by mainstream society.

Individuals who were born blind or became blind early and later became deaf are more likely to use spoken language as their main means of communication. Due to their hearing loss, they might later add some signs, fingerspelling, Tadoma, or other forms of manual communication (e.g., printing on the palm) to aid in communication. These individuals tend to identify with and therefore associate primarily with the blind community, individuals from the mainstream culture, or the disabled community. Due to their deafness they are later also likely to associate with the Deaf-blind community where they are more likely to have more equal access to communication.

Individuals who are born or become deaf early and later become blind are likely to use a signed language as their main communication method and therefore associate with other members of the Deaf community and be mostly involved in Deaf culture. Because of their ties to the Deaf community, they are likely to remain involved with Deaf culture, but later also be involved with the Deaf-blind community. At least one scholar has argued that a substantial number of deaf individuals who become blind feel ostracized by the Deaf community and thus withdraw and associate more with the Deaf-blind community.

The individuals who are born deaf-blind are likely to associate either with the Deaf community, the blind community, the Deaf-blind community, the disability community, and/or mainstream society. It will most likely depend on the severity of their hearing and vision loss, on the community in which they grew up, on the type of schools they attended, and on which language they prefer to use. For example, individuals who consider their deafness to be the most important aspect of their identity and who use a signed language are

likely to associate with the Deaf community, whereas individuals who have significant amounts of residual hearing and vision and primarily rely on spoken language will associate mostly with mainstream society.

The individuals who spent most of their lives as sighted and hearing individuals and then all of a sudden became Deaf-blind are most likely to feel the most disoriented regarding culture and community membership. They are most likely to have spent most of their lives in mainstream society and to have used spoken language to communicate. As Deaf-blind individuals, they are likely to need to learn alternate methods of communication and depending on which of the plethora of options they choose and prefer they may join any of the communities. This group is especially likely to be drawn to either the Deaf-blind community or the disability community because in both of these communities a diversity of communication options seems to be accepted allowing these individuals full participation and access.

When considering deafblindness from a developmental perspective, it is possible to consider deafblindness from both the medical and the cultural or social perspectives. Researchers following the medical perspective, the most common point of view within the field of developmental science, tend to focus on the deficits of deaf-blind children and on the delays they experience in comparison to their typically developing peers. Within the developmental science framework, the cultural model, however, allows researchers to study the plasticity of development in general and to learn about the development of identity and cultural affiliation of minority groups.

From a developmental medical point of view, the most important aspects of deafblindness are the age of onset and the severity of the hearing and visual impairments. According to the developmental model, the two sensory impairments multiply the effects of one another and intensify the impact each one has on an individual. Having two impairments likely inhibits the compensation of one impairment through the use of the other (e.g., compensating for deafness by lipreading). Consequently, the earlier the auditory and the visual impairments occur and the more severe the level of each impairment is, the greater are the consequences on development.

Deafblindness is likely to affect cognitive, language, social, and emotional development. Individuals who are born both deaf and blind commonly experience significant delays because they are not able to observe and thus learn about the world as readily as sighted and/or hearing infants. According to Piaget, whose research focused on cognitive development, individuals need to gain experience within their environment to acquire the skills and the knowledge necessary to successfully complete the tasks for each of the four developmental stages. The sensorimotor period, the stage between birth and two years of age in which infants learn about the basic properties of objects, progresses through a series of substages, and culminates in the infant's ability to mentally represent objects. Infants acquire object permanence, the knowledge that objects continue to exist even when they are hidden. This is considered a difficult task for blind and deaf-blind infants because they only learn about the world within their reach. There are limited or no visual and/or auditory clues to provide them with information. Interesting objects within the environment encourage infants to investigate their surroundings. For blind and deaf-blind infants, this is not the case. Therefore, they spend a lot of time in the position they were put down in often resorting to self-stimulating behaviors. Similar observations can be made throughout deaf-blind children's development. With increasing age, the delays become greater and it becomes difficult for them to catch up to their peers. It is therefore beneficial for the development of deaf-blind infants that they are diagnosed and that age-appropriate stimulation is started young.

Deaf-blind children's language development is also at risk for significant delays. First, deaf-blind children, as blind children in general, are likely to be delayed in their mental representation abilities and subsequently in their language development because language requires mental representation and actually is considered a complex form of mental representation. Second, deaf-blind children with a significant hearing impairment tend to be delayed in their language development because they are likely to not have access to language. They cannot hear spoken language and they cannot see and thus imitate gestures or signs. Some deaf-blind infants, similarly to deaf infants, may develop their own rudimentary gestures for certain

objects or events. However, due to the likely lack of mental representation skills, infants born deaf-blind are even less likely than deaf infants to be able to string together individual gestures to form complete thoughts or express desires. On the other hand, those young children who either became deaf-blind after already acquiring mental representation and those who have significant residual vision and/or hearing are likely to learn mental respresentational skills more easily than their peers who were born completely deaf-blind.

When discussing the medical model within the field of developmental psychology, it is important to ask whether this model provides a complete picture with all the answers. Most likely this is not the case. As research studies have shown, the environment is essential to the prediction of later outcomes in children. This is particularly the case for deaf-blind children. If deaf-blind children are provided with an accessible language and an accessible environment in which they are stimulated and encouraged to investigate their surroundings, they learn at a similar rate as their hearing and sighted peers.

In summary, deaf-blind individuals represent a highly diverse group of individuals. Deaf-blind people can acquire their impairments at different ages. They have varying degrees of hearing and vision impairments, which can affect their developmental pathways. They may communicate in a plethora of ways. They can identify as members of a variety of cultural groups. Each one of these factors can have an impact on the individual who is deaf-blind. As will all people, it is important to view and respect each deaf-blind person as an individual.

—Ingrid C. Hofmann

See also Blind, History of the; Laura Dewey Bridgman; Helen Keller.

Further Readings

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