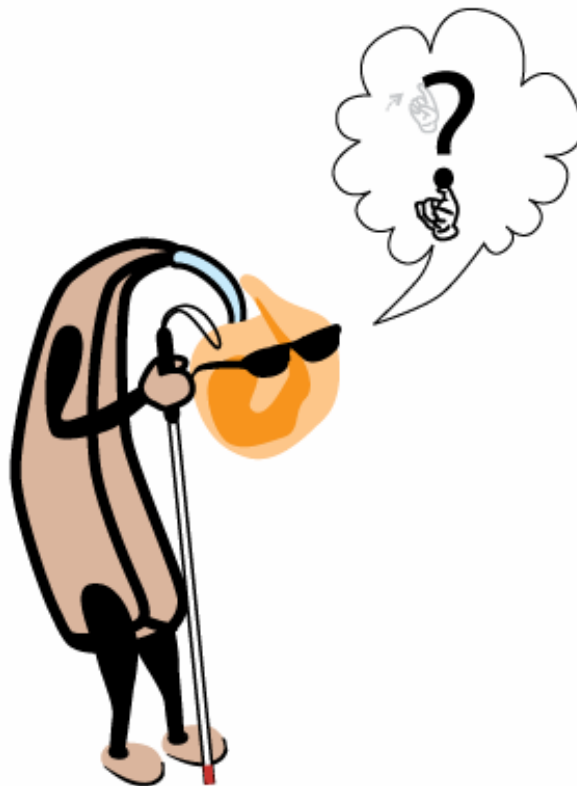


Chapter Two

Who are the DeafBlind?



What Does It Mean to be DeafBlind – Really?

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Much has already been said about the diverse makeup of the population of consumers who are deafblind; however, what remains unclear for many service providers, educators, family members, and VR counselors specifically is who are the people that meet the criteria to be included amongst the ranks of the deafblind population (Ingraham, Carey, Vernon, & Berry, 1994). The recent change to the coding system for deafblindness used within the Rehabilitation Services Administration (RSA) has created some confusion regarding the specific *identity* of the average deafblind consumer. This brief chapter will attempt to clarify the term “deafblind” and aid professionals, family members and students in understanding its use and benefit.

As was noted in the first chapter of this monograph, the term deafblind is comprised of four different categories of individuals. (See Table I) Many professionals may operate with the misconception that an individual with whom a verbal dialogue is possible or who utilizes his/her vision for reading and traversing the community could not possibly be considered deafblind. On the contrary, according to the federal definition, many individuals who are recognized as deafblind retain very usable vision and hearing; and to the average person may **appear** to have no obvious limitations. It is for this reason that a more functional explanation of the term “deafblind” will be discussed here.

Notwithstanding, the four categories of deafblindness have greatly helped to more succinctly define the population; however, these categories might seem, to the untrained professional, to be too inclusive and broad. If one keeps in the mind the basic definition of the term there would be less opportunity for confusion and mislabeling of students. Simply defined, deafblind means the co-existence of a significant vision and hearing loss which impacts an individual’s ability to function in areas of daily life including, but not limited to: communication, education, employment and ability to access basic community resources (Adler, 1987).

The individual who is born without any usable vision or hearing is often who comes to mind when we think of persons who are deafblind. While rare, it is not uncommon for a person, as a result of maternal illness, gestational trauma or birthing complications, to be born without the ability to see or hear anything at all. With early and proper education, these individuals can grow up to lead very satisfying and productive lives. Specialized training, adaptive equipment, and personal motivation have enabled many such individuals

to not only thrive, but to fall in love, marry and raise their own families as well. While functioning with total independence may be a challenge for this group of students, as would be for any person, support services from community based service programs, religious institutions, volunteer organizations, friends, families, and even paid staff can afford these students full access to the community. Like Helen Keller, many deafblind students find attending academic programs more achievable with the support of a *companion* or *Intervenor* (a term that has become more widely recognized in education). This refers to an individual who essentially functions as the eyes and ears for the deafblind student. More specifically, the Intervenor provides the deafblind student with access to information which he is unable to hear, see, or otherwise gather on his own (Olson, 2004).

Some of the stories profiled in this monograph will resemble the stereotypical image that comes to mind when the term deafblind is used.

Table 1

Categories of DeafBlindness	Common Etiologies	Personal Adjustment Support	Orientation and Mobility Needs	Independent Living Skills Training	Communication Needs
Congenitally DeafBlind	Congenital Rubella Syndrome, CMV, Premature Births, etc.	Early intervention services for student and family members.	Early intervention services for student and family members.	Early intervention services for student and family members.	Early intervention services for student and family members. Touch cues, object cues and manual communication.
Congenital Deafness and Acquired Blindness	Heredity, Usher Syndrome, Alstrom Syndrome, Alport Syndrome, Trauma, illness, accident, advanced	Personal and vocational adjustment to blindness training.	Orientation and mobility training using techniques, devices and specialized transportation services.	Training in cooking, cleaning, labeling, eating and grooming skills required for independence.	Alternative forms of receptive and expressive communication including, English, braille, tactile sign language, tactile fingerspelling, Print on Palm, adaptive face to face,

	age, etc.				telecommunication and Internet access technology.
Congenital Blindness and Acquired Deafness	Illness, trauma, accident, heredity, medical complications, advanced age, etc.	Personal and vocational adjustment to deafness training.	Adaptive technology devices to compensate for hearing loss, including: assistive listening devices, digital hearing aids, Cochlear Implants, adaptive mobility aids and specialized training by O&M instructor familiar with the unique mobility needs of deafblind students.	Adaptive technology and techniques for food shopping, safe food preparation, cooking, clean-up, home repairs and labeling food containers.	Alternative communication systems, devices, techniques for receptive and possibly expressive communication, including tactile sign language, tactile fingerspelling and finger braille.
Acquired Deafness and Blindness		Personal, vocational and mental health counseling to	Adaptive technology devices to compensate for hearing		Alternative forms of expressive and receptive communication, including tactile

		address adjustment to deafblindness.	and vision loss, including: assistive listening devices, digital hearing aids, Cochlear Implants, adaptive mobility aids and specialized training by O&M instructor familiar with the unique mobility needs of deafblind students; braille instruction,		sign language or tactile fingerspelling, braille, Print on Palm, adaptive communication devices and software for magnification, speech output and print translation.
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However, there are additional stories of successful students that may change the opinions of those who have previously believed/thought that deafblindness was a rarity or a phenomenon.

The scenarios below are meant to provoke thought and to give a more clear understanding of the wide-ranging degrees of deafblindness.

Scenario A

Any deaf or hard of hearing person preparing a meal which required fresh onions has experienced the effects that dicing an onion can have on one’s ability to see. The deaf

person may tell you that he has experienced what it's like to be temporarily deafblind. Once the fumes from the onion make contact with the tear fluid of the eyes, excessive secretions will follow, resulting in temporary loss of visual acuity. For a person who is deaf, this loss of visual acuity has instantaneously impeded any ability to receive information through the modality normally preferred by deaf individuals. Even though the individual may still have the ability to see some things, images are so distorted and blurred that the result is what is medically termed *legal blindness*. The individual can see well enough to maneuver to the sink to wash out his eyes; however, functioning with this degree of vision loss on a daily basis would require a great deal of "personal adjustment" training. Personal adjustment training not only includes learning how to accept this change in vision and possibly fluctuating vision, but also include training in adaptations or modifications to daily activities. For example, locating the vegetables from the refrigerator would not only require knowledge of the kitchen's layout, but the person would have to know where the vegetables were stored inside the refrigerator. If the vegetables require peeling, more training would be needed to know which utensil is the safest for the chore. How will the person know if all the skin has been removed from the vegetable? What is the least messy way to mix dry or wet ingredients? If cooking is required, will the microwave or stove top be used? How will the person know to set the cook time for the microwave? How can he cook on the stove without getting burned? What about setting the table and cleaning up afterwards? How will the individual store the leftovers? Who will clean the dishes and the prep area? As the person prepares for the next day, how will he know which clothes to select and if the selected items are color-coordinated? If the person wanted to chat with a friend on-line, how would he connect to the Internet?

From this simple scenario of an individual who is already deaf experiencing extremely blurry vision, you have witnessed a type of deafblindness. The individual retained some useable vision; however, the vision which remained was so impaired that personal adjustment to blindness training would be required to perform very basic daily activities.

Scenario B

Likewise, if a person who is already blind attends a loud rock concert and is seated close to the speakers, he/she may experience temporary hearing loss during the concert and for some time following. The buzzing and ringing in the ears may impede the ability to have normal conversations with friends and loved ones. This individual may be required to use braille or the less appropriate shouting for receptive communication until such time that the

hearing becomes more reliable. If the ringing in the ear stops and the person discovers that it is no longer possible to hear speech spoken at a normal conversational level, the use of some type of assistive listening device may be required. Also as a result of this newly acquired hearing loss, when this person with congenital blindness and acquired deafness leaves home to attend school, it may be observed that his previous ability to accurately locate traffic sounds and other environmental noises is no longer reliable. Once in the classroom, the individual may be unable to hear the instructor even after having his seat moved closer to the front of the classroom. Talking on a cell phone may also become difficult as a result of this newly-acquired hearing loss. Dining out with friends may be nearly impossible due to the loud voices of the other restaurant patrons and wait staff. How would this person address these new impediments to independence? What other types of reliable and more efficient means of receptive communication should the individual consider? What types of adaptive technologies are available to help a student in a situation such as this to get around in the community? How will the student be able to continue with education? As was seen in the previous example, personal adjustment training will be needed. This specialized training will include exposure to alternative forms of receptive communication and possible training in the use of assistive listening devices.

Scenario C

Another type of functional limitation to consider would be associated with a person who is the unfortunate victim of a traumatic event (i.e., explosion, gun shot, or serious illness). To be more specific, let's say the individual is involved in an automobile accident. The person who is a passenger in the front seat of the automobile is thrown into the windshield when the driver loses control of the vehicle on an icy surface. The lacerations and head trauma result in damage to the seventh and eighth cranial nerves. The person becomes deafblind in an instant. Once a vibrant and curious student, the individual is now unable to hear or see anything. As the wounds and lacerations are attended to in the hospital emergency room, the individual can sense the presence of others. However, he is unable to hear what is being said and can not see what activities are taking place. How will this person know what comes next? How will the individual locate the restroom? How will this person feed himself? How will the hospital staff communicate with this person? Will this individual be able to return to a life of independence? What type of work will this individual be able to perform now? Again, personal adjustment training will be required to enable the student to regain his independence and ability to access his community.

Each of these brief scenarios describe individuals who once may or may not have been considered deafblind – but are now faced with the reality of combined vision and hearing loss and the need for personal adjustment training to deafblindness to identify and introduce any viable alternate forms of receptive and possibly expressive communication to address their individual needs. Normal activities of preparing a meal, accessing the community, and working, interacting with friends, or attending school have been greatly affected by the inability to see or hear clearly. These scenarios **are** examples of a few realities of deafblindness.

In addition, deafblind students include individuals who are born deaf and slowly lose their vision due to Usher Syndrome, as well as individuals who were born during the Rubella epidemic of the 1960s with complete loss of both vision and hearing. Even students with neurofibromatosis have been identified within the deafblind population. Using the term deafblind in the first two scenarios implies that the individual, after acquiring a secondary sensory loss, will require some degree of personal adjustment training. Access to adaptive communication methods, assistive technology, specialized employment adaptations, education and maybe even mental health counseling are invaluable tools to help the individual identify coping strategies that can aid him with his personal adjustment (Miner, 1996; Vernon and Annala, 1982). Also, it will be essential for this person to learn how to cope with frustrations, depression, and isolation often encountered when trying to function independently within a society that is not readily accessible. Any professional who has experience working with a student facing a similar reality of acquired deafblindness should immediately consider the student's training needs relative to personal adjustment training and possible therapeutic counseling.

Although this monograph targets the needs of students and young adults of transition age, in actuality the fastest growing segment of the deafblind population are individuals who make up the Baby Boomer generation and children of the Great Depression. The risk of age-related vision and hearing loss is increased in these two groups of consumers. In the year 2006, it was estimated that every day 8,000 individuals reached the age of 60 (US Department of the Census). Every new day brought another 8,000 potential members to the population of the deafblind who may require personal adjustment training as well. This is due in part to Baby Boomer's history of spending long hours over many decades sun-bathing, which has now been linked to macular degeneration later in life (Macular Degeneration Association). This fact coupled with prolonged exposure to loud music at rock concerts and the use of headphones for personal stereos, have resulted in

auditory nerve damage and permanent hearing loss for many Boomers. It is ironic that this group of aging consumers who, as they transition to retirement or continue working beyond the age of 70, will be in great need of the identical support services, adaptive communication methods, and assistive technology used by transition-aged high school students profiled in this monograph.

Nonetheless, the particular area of transition that will be focused upon in this monograph *is* specific to persons who are young adults; yet the relevance for younger school age children and aging Baby Boomers will become obvious as you read through the various chapters and student biographical essays. Personal adjustment training including self identification, self awareness, specialized support services, and early preparation have been proven to appreciably enhance the quality of life outcomes for students and individuals of all ages who are coping with the reality of impaired vision and hearing.