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DEAFENED ADULTS: ADJUSTING TO A NEW WORLD

POINT OF VIEW¹

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Abstract

The task of assisting deafened adults in adapting to the loss of receptive communication, as well as the resulting social, psychological, and employment changes presents many challenges to professionals in the field of deafness. People who became deaf after the age of 18 years have to make adjustments to offset their loss of receptive communication skills. The process of learning to accept and cope with hearing loss involves many adjustments by the deafened individuals and significant people in their lives. Rehabilitation professionals need to have an understanding of the adjustments being faced by deafened individuals and be prepared to provide them with useful information related to communication, accommodation and other services that may be needed.

benefit from services rehabilitation counselors typically provide to clients who are deaf or hard of hearing. People who have recently become deaf must make unique adjustments in their personal, social, and vocational lives that require special attention from professionals in deafness rehabilitation, social work, and counseling.

In their national census of the deaf population, Schein and Delk (1974) found that more than 75% of all deaf persons lost their hearing after 18 years of age. However it was not until the 1980s that the needs of the deafened population began to receive recognition. In 1983, the American Deafness and Rehabilitation Association (ADARA) conference included one workshop that focused on the needs of deafened individuals. For several years, Joe Weber authored a regular column in the NAD Broadcaster that offered his perspective on the needs of deafened adults. In 1984, the National Association of Deafened People was founded in the United Kingdom. In the United States, the Association of Late-Deafened Adults (ALDA) was formed in 1987. Beginning as a social group, ALDA grew from 13 Chicago people to an international organization with more than 600 members. The growth of this organization exemplifies the large number of deafened individuals seeking assistance and support.

"Deafened" and "late-deafened" are terms that deafness rehabilitation professionals are beginning to encounter more frequently. The terms most often refer to people who acquire a profound hearing loss after leaving high school. These people usually do not know sign language and do not receive substantial benefit from assistive listening devices for receptive communication purposes so they are not able to

¹This section provides a forum for exchange of reasoned ideas on all sides of issues in the area of deafness. The opinions expressed in this article, and others that appear in *Point of View*, are those of the authors and should not be considered the position of ADARA. The editors welcome responses to the opinions expressed in this section.

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Background

The process of becoming deaf occurs in different ways. With an abrupt hearing loss, a person can go from normal hearing to audiologically deaf in a short time span. Other people experience the loss gradually and go from normal hearing to hard of hearing to deaf, while still others have been hard of hearing since an early age, and their sense of hearing decreases until they can no longer effectively receive verbal communication. This process, whether gradual or abrupt, requires deafened people to make significant adjustments for communication purposes and has a profound impact on other aspects of their lives.

Persons who become deaf may have difficulty assimilating into either the deaf or hard-of-hearing worlds. The lack of an effective mode of receptive communication makes it difficult to communicate with associates from their former world (hearing or hard-of-hearing) and, understandably, it is difficult to immediately learn sign language. The communication difficulties leave deafened adults in what is, in essence, a "new world", set aside from both the deaf community and the mainstream hearing culture.

Group communication is a more difficult adjustment than one-to-one communication. There are several factors that explain this difficulty. First, it is easier for the deafened person to concentrate on what is being said when only one other person is involved in the communication process. Second, one person is often more willing to adjust the speed of communication, speak or sign more slowly, or possibly write if necessary. This willingness to slow down the speed of communication is not as common in a larger group. Even when all of the people involved in the group are aware of the deafened person's communication difficulties, this adjustment is not often made. Occasionally, one member of the group may speak slowly or sign a specific piece of

information that he/she wants the deafened person to understand, but this type of communication can be embarrassing for the deafened individual because it makes everyone in the group aware of the hearing problem. Also, the feeling of being different or not being able to understand is not easy to accept. The following quote from Bill Graham, co-founder and first president of ALDA, explains this feeling.

My name is Bill G. and I am a late-deafened adult. Whew! There, I said it: I'm deaf. The hardest part is over. Let's party! No, really—I've always had a hard time saying that word: deaf, deaf, deaf. Eight years ago I wouldn't have touched that word with a forty foot pole. It was just too embarrassing to admit that I couldn't hear. And I'm not a guy who gets embarrassed easily.

... When I gradually lost my hearing after high school, I was terribly embarrassed and ashamed. That's not very logical because it wasn't MY fault that it happened. I had nothing to do with it—it just happened. (Graham, 1991, p.1)

Adjusting to Deafness

There are numerous adjustments a deafened person needs to make to counteract his/her hearing loss. Hearing loss and the resulting loss of receptive communication affects every aspect of an individual including self-esteem, educational activities, employment, social life, leisure-time activities, and personal/family relationships. Learning to cope with the necessary adjustments is a major task, not only for the deafened individual but also for the significant people in his/her life. Making the adjustment to deafness is similar to coping with other types of personal losses.

Elizabeth Kubler-Ross (1969) developed a grief process model with five stages: denial, anger, bargaining, depression, and acceptance. This

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model was developed to describe individual's reactions to terminal illnesses, but it may be applied to loss of hearing. A person who becomes deaf experiences all of these stages to some extent. Hearing loss is easy to deny as a person can pretend to be distracted, blame outside noise, or blame the speaker as reasons for not understanding. Feelings of anger and "Why me?" are frequently experienced by deafened individuals. The bargaining stage may not be experienced as frequently, but it is a fairly good bet that deafened people have said prayers or considered making extreme promises if their hearing were returned. The feeling of depression related to hearing loss comes from the feelings of isolation and the inability to communicate as in the past. The feeling of acceptance of hearing loss is difficult to measure. As with accepting death or any other traumatic loss, a hearing loss is most probably never celebrated, but the deafened individual may arrive at a point where the hearing loss can be accepted or integrated into other life experiences and goals.

Building on the Kubler-Ross model, Zieziula and Meadows (1992) identified five major adjustment themes that deafened individuals confront: *spectrum of emotional responses, secondary losses, confusion of identity, acceptance, and need for competent professional assistance from medical and social-support personnel.* These themes were developed based on interviews with 11 deafened individuals in an effort to better explain the emotions involved with hearing loss than the Kubler-Ross model.

Personal Adjustments

The loss of hearing requires major personal adjustments in almost all phases of an individual's life. The loss of receptive communication has a significant impact on an individual with the first reaction being to think of all the things one can no longer do: listen to the radio; talk on the phone; talk to family, friends, and co-workers; casual

conversation with clerks and waitresses; and numerous other communications that were always taken for granted. With the onset of deafness, the only person with whom you can communicate effectively is yourself.

Deafened adults may initially view deafness as a temporary condition that can be cured by medication or surgery. They may dream of waking up and being able to hear on the telephone and/or understand what people are saying to them. Since deafness is viewed as temporary, people prefer to hide it rather than admit it. The individual may display more anger related emotions as it becomes obvious that deafness is not temporary.

As deafened adults realize there are numerous things they can no longer do, self-esteem can plummet, leading to feelings of depression and guilt. An individual may feel guilty when reviewing past actions and he or she may wonder if there was anything that could have been done to prevent the hearing loss. "If I had gone to the doctor earlier, if I had stayed home instead of going out, if ... , if.." There are many questions people ask themselves after something traumatic occurs.

Social Adjustments

Deafness is invisible and easy to hide from other people. It is common for people who recently have lost their hearing not to inform their peers of the hearing loss. The inability to communicate with family and friends results in a feeling of isolation. When one is not able to communicate effectively in social or employment settings as before, it is difficult to feel comfortable in those environments. Deafened adults struggle internally as they attempt to identify social and leisure time activities that are comfortable for them.

Listening to the radio is one example of an activity that is no longer accessible. A person who enjoyed listening to music on the radio may still

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have the radio turned on but most probably he/she is not aware of the actual program or the name of the song. The radio could be all static and the deafened person would not know it. Listening to sports events, music, news programs, and call-in shows on the radio is no longer an option. The individual needs to identify new ways to stay involved in previous interests or develop new interests.

Family Impact

The onset of deafness affects not only the deafened individual but also impacts parents, spouses, siblings, children, and significant others. Having a deafened person in the family will disrupt the established communication patterns and routines. Family relationships may be disrupted as communication becomes more labor intensive. Writing notes, speaking slowly to facilitate lipreading, and learning sign language are examples of changes that may be needed to develop effective communication. The deafness of one family member may create the feeling of extra responsibility (i.e., interpreting, making calls, serving as intermediary) for another family member. To avoid feelings of resentment and/or anger, these issues need to be addressed and resolved. If the hearing members are expected to perform new additional tasks, then the deafened family member may need to assume tasks previously assigned to the hearing member in order to maintain a balance of responsibilities.

There may be a similarity between families of deafened adults and the families of some deaf children. If the family does decide to learn sign language, they frequently learn only basic survival signs or homemade signs. A similar problem is that of families not having enough information to make decisions concerning available options and services.

Communication Options

Most deafened individuals retain their speech skills so they are able to continue using speech in the hearing world. However, deafened individuals are aware of the lack of information they are receiving and, consequently, the need to develop alternative receptive communication skills. There is a strong desire to find a "cure" for deafness by developing alternative methods of communication that would allow the late-deafened person to continue functioning in the hearing world.

Hearing aids/cochlear implants and lipreading are viewed as "cures." When a person first loses his/her hearing, a hearing aid may be the first "cure" considered. Most people have read the advertisements stating, "If you can hear sounds but not understand speech, this hearing aid is for you" or words to that effect. When a person acquires a profound hearing loss, a hearing aid is more likely to assist with hearing environmental cues than understanding speech. Deafened adults who are seeking the "cure" will experience frustration and anger when the hearing aid does not meet their expectations. With advanced technology, cochlear implants also represent a "cure" that may or may not be effective.

Lipreading or speechreading is also regarded as a "cure." Deafened individuals believe the myth that "all deaf people can lipread" and become frustrated with themselves when they are not able to develop this skill. When a deafened individual is unable to easily acquire this skill, the results are additional frustration and anger.

Sign language is a third communication option that may be recommended, but it takes time to learn. Deafened individuals may be reluctant to develop this skill as it will make them "different." There is often limited opportunity for deafened adults to learn and/or practice sign language as they do not know other people who use it.

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Deafened adults and their families often need exposure to other deaf or deafened adults who use sign language before they feel comfortable with this option.

Accepting Deafness

Accepting deafness is a process that requires a varying amount of time. In most cases, it takes an individual two to three years to integrate deafness into their lifestyle. This does not mean the individual cannot function prior to this time but that acceptance is a lengthy process. It is unrealistic to expect the individual to make the necessary life adjustments in a time frame measured by weeks or months.

Participants involved in the Zieziula and Meadows study expressed that while they had generally come to accept their deafness, there was concern that family members and significant others had problems accepting their physical and social changes. The necessary adjustments need to be discussed and agreed upon so that all family members feel comfortable with their expected roles.

Service Needs for Late-Deafened Adults

Professionals working with persons who have become deaf need to have a proper understanding of the adjustments just discussed and be able to make appropriate referrals for assistance. If the hearing loss is very recent, the information being provided may not be absorbed due to the individual's denial of hearing loss. A deafened individual needs time and assistance in dealing with the various emotions involved. Social services and rehabilitation professionals need to be aware of the impact of communication loss and the strong desire to find a "cure" that the deafened individual may be seeking.

The desire for a cure is often unrealistic. The psychological adjustments involved with accepting

the reality of deafness and changing one's lifestyle may require professional counseling assistance. The deafened adult and his/her family/significant others need information about the variety of services and assistive devices that are available as well as exposure to other people who are deaf, hard of hearing, or deafened. This exposure to people facing similar difficulties will assist in making necessary adjustments regarding the individual's identity and where he/she wants to fit into the world.

In order to provide competent professional assistance, professionals working with deafened adults must be aware of five factors and their implications for service needs. The five factors to be considered are: age of onset, time elapsed since loss occurred, etiology of loss, degree of loss, and family reaction. The age of onset will have an impact on rehabilitation professionals in determining a plan for services. For older individuals with an established career, the focus should be on possible accommodations to continue doing their work. The deafened adult will need information on assistive devices as well as the legislation (Americans with Disabilities Act, Rehabilitation Act of 1973) concerning the responsibilities of employers to provide accommodation. While legislation strongly supports the employer's requirement to provide accommodation, it is possible that the deafened person will not feel comfortable with the communication demands of the job and will prefer to change careers. The rehabilitation professional needs to understand this discomfort with communication may be considered normal and should discuss all the implications of a career change. Modification of job duties and reasonable accommodation will allow most individuals to maintain their employment, if they desire.

The elapsed time since the hearing loss occurred will provide some idea as to where the person may be with the grief process in dealing with his/her loss. Regardless of age, a person will

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need assistance in adjusting to the hearing loss. If the loss was abrupt and traumatic, there is a need for assistance in making the psychological adjustment to deafness. There is a stage of denial, regardless of the degree of loss, in which an individual will view his/her deafness as a temporary condition. In some cases this is encouraged by doctors' reports, friends, and relatives. It is a rare situation where deafness is only temporary so the denial stage must be confronted and worked through by the individual. Often exposure to other deaf or deafened individuals will assist with this adjustment process because it allows the individual to see that he or she is not alone and that deaf and deafened people can lead successful lives.

The adjustment process is made difficult by the lack of receptive communication skills. How can one effectively counsel a person who has no receptive communication skills? The counselor/therapist and deafened person need to develop a system that ensures effective communication. This effort requires patience on the part of the counselor/therapist because writing is often the only effective communication mode, and writing requires increased time. Use of real-time captioning with a typist or court reporter is one possibility for communication. This would require an adjustment on the part of the counselor and client in having a third person involved in the therapeutic process. If both counselor and client have typing skills, they could type to each other using a computer keyboard and monitor.

Informational Needs

To further provide competent services, professionals working with deafened adults must address the information needs they have. Three areas in which late-deafened individuals need information are communication, employment, and socialization.

Communication

Deafened adults need accurate and complete information regarding all the communication options available to them. The misconceptions regarding hearing aids and lipreading/speechreading must be clarified with the [possible benefits and consequences being properly explained. Other communication options include assistive listening systems (FM, Infrared), cochlear implants, and sign language.

Initially, the deafened adult may not be satisfied with any of these systems because he/she is looking for the "cure" that will restore their hearing and allow them to return to their previous levels of receptive communication. Partial improvement may not be satisfactory. It is important that deafened adults have accurate and complete information before making the choice that is most appropriate for them. All the systems have pros and cons that need to be clarified to the deafened individual. Once a system has been selected, the deafened individual will need a training program to learn to use the selected system and make the necessary adjustments.

Deafened adults need information on the technological devices available to assist them with environmental communication. These devices include flashing signal lights (telephone, doorbell, alarm clocks, smoke detectors, etc.), telecaption decoders, text telephones (TTY), and other assistive equipment that is available. These devices provide substantial assistance, but most recently deafened adults are not aware of their existence. Fax machines and electronic mail systems are common forms of communication technology that are helpful to people who are deaf.

A new communication method that is being developed and refined is real-time captioning. Simply stated, this process involves someone keying what is being said with the words appearing on a monitor. This can be done with a typist using a computer keyboard and monitor or a TTY or by hiring a court reporter who has

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specialized equipment to provide computer assisted real-time (CART) captioning. Most typists are unable to type as fast as people speak so there are limitations involved with this system. The CART system is more effective than typing on a computer screen but also more expensive due to the skills and equipment required. Rehabilitation professionals should familiarize themselves with the technology and the resources available to them. Deafened individuals benefit from captioning services the same way deaf people benefit from interpreters. Local resources may need to be developed to provide this service.

Employment

Information about assistive devices is also important in making decisions regarding employment. Many deafened adults are able to retain their jobs but need information about the laws pertaining to reasonable accommodation (Americans with Disabilities Act and Section 503 of the Rehabilitation Act of 1973). Flashing signal lights, TTYs, and knowledge of the use of telephone relay systems will help many deafened employees retain their jobs. An effective communication system with employers and supervisors needs to be determined. Electronic mail systems may enhance communication if available. The potential benefits of this type of communication to all staff members should be explained to employers. The rehabilitation professional should provide the employer with additional resources, such as the state attorney general's office, centers for independent living, and regional access centers who can provide additional information related to legal responsibilities and reasonable accommodation.

Most deafened adults are able to read and write so written communication is often effective for brief communications. If longer meetings are required, other communication options need to be made available. Real-time captioning is one meeting accommodation option that is often

effective for deafened adults. Captioning is considered an auxiliary aid that can be provided to assist an employee perform his or her job under the Americans with Disabilities Act.

Deafened adults who are unable to continue their employment due to the need for hearing or verbal communication where no accommodation can be made will require training to learn a new vocation. This training will be more complex because the person is adapting to a new method of receptive communication. The possibility of changing to a similar job that can be adapted with reasonable accommodation should be explored.

Socialization

The social issues facing the deafened adult are most often related to communication. Most of these people have never known a deaf person, and they are not aware of Deaf culture or the Deaf community. Deafened individuals identify most strongly with the "hearing" world.

With time and information, the deafened adult becomes aware that there are social groups for people who are deaf. The individual must then decide where he/she feels most comfortable. This choice is often dictated by the individual's most effective communication method. Those persons who are able to lipread well continue to socialize with the same friends they had before losing their hearing. Individuals who are able to learn sign language may choose to socialize with deaf people in their community. Most often, deafened people fall between the cracks. They do not develop the communication skills that allow them to interact comfortably with either hearing or deaf people and become socially isolated.

Deafened adults tend to feel most comfortable with their peers. Having the opportunity to interact with other deafened adults is important. This group of people share similar experiences, especially in dealing with the frustrations related to deafness and the lack of receptive communication. This is where the value of a support group

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becomes important. It was the comfort level experienced with a peer group that led to the founding of the Association of Late-Deafened Adults (ALDA) in 1987. The general purpose of ALDA is to provide education, advocacy, role models, and support for late-deafened adults. ALDA supports a stress-free communication philosophy of "whatever works" for the individual whether it be sign language, lipreading, assistive listening devices, or written communication. ALDA publishes a quarterly newsletter that includes the writings of deafened adults who share their experiences and how they have learned to cope with deafness. This type of information can be a valuable resource for people who recently lost their hearing. The concept of sharing is further enhanced for those who are able to attend ALDA's annual convention, ALDAcon. ALDAcon allows deafened individuals the opportunity to interact with their peers and share first hand experiences of the frustrations and barriers they have encountered.

Conclusion

The task of assisting deafened adults in adapting to the loss of receptive communication, as well as the resulting social, psychological, and employment changes presents many challenges to professionals in the field of deafness. This task will involve the development of new resources and present new challenges in communication access. The technical capabilities exist, but the financial resources continue to be limited. It is important that deafness professionals be aware of the needs of the late-deafened population and assist them in making the adjustment to their new world. The needs of late-deafened adults are different than those of individuals who are deaf or hard of hearing. Deafness rehabilitation professionals need to be aware of this distinction when selecting and purchasing services. An effective rehabilitation outcome depends on it.

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