

Adjusting to Hearing Loss: The Trials and Tribulations of a Deafened Adult

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The most effective way for me to begin explaining the issues related to working with deafened individuals is to describe my personal experiences in becoming deaf. I became deaf at 18 years of age due to a viral infection and high fever. I was a freshman in college and beginning to develop my own life plans. Having grown up in an Iowa farm community, I had no previous experience with persons who are deaf. I was also relatively unexposed to persons with disabilities or persons of other cultures.

I point out this lack of exposure to disabilities because the majority of persons who become deaf or are in the process of losing their hearing have had no previous contact with person who are deaf. They may have had contact with elderly persons who are hard of hearing or deaf but that is a normal expectation. People do not expect to lose their hearing as a young adult or in middle age.

As an 18 year old college freshman I was unable to accept my hearing loss and was living in a state of denial. I DID NOT WANT TO BE DEAF! Deafness is something that happens only old people. It was not supposed to happen to me. I did not tell anyone that I could not hear. I continued to attend classes and did not inform my instructors, classmates, or friends of my hearing loss. Some of them noticed there was a problem but I was not about to tell them.

I did not go to a doctor or seek assistance. The first time I went a doctor was when my parents took me during spring vacation. They noticed my hearing problem during my week at home. They probably viewed my failure to respond as being a teenage rebellion and I was blaming them for not telling me things or not speaking clearly. Internally, I was aware there was a problem but was not willing to admit it.

This first trip to an otologist that provided me with my first experience with doctors who have only a medical perspective of hearing loss. The doctor examined me and could not find any medical problem. He observed some scar tissue that was related to an infection but there was no visible problem with my ears. This doctor then suggested that I may be worried about the military draft (this was 1971 and the time of the draft lottery) and my hearing loss was a psychological reaction. I admit that I was not interested in being drafted but, 25 years later, it seems obvious that my deafness was not psychological. In private, the doctor also asked me if I had been smoking marijuana and if that may have been the cause. I had not yet been exposed to marijuana at this time so it was not a possible factor.

The feeling I remember most is that I did not want to be deaf. I was uncomfortable trying to explain my deafness to friends who had known me all my life. It was awkward to explain my hearing loss to anyone. I became isolated and chose to avoid obvious social situations if possible. In social situations, I was bluffing my way through conversations, usually smiling and nodding my head to comments from

others. It was very embarrassing to deal with these situations and I am sure that I made a fool of myself many times over with inappropriate comments.

Looking for a Cure

I did not want to be deaf and was looking for a cure. I was only able to see the negative aspects of being deaf. I could not understand classroom lectures, residence hall conversations, television programs, radio programs, or use the telephone for conversations. I was depressed because I had become very dependent on the radio for entertainment such as baseball, basketball and football games. I was focusing on the things I could NOT do and was ignoring things that I could do.

While looking for a cure, I had to deal with communication myths that I had developed as a hearing youth. It was my belief that a hearing aid would solve all my problems. Everyone has read the advertisement that states something like “If you can hear sounds but not understand speech, this hearing aid is for you.” That described my hearing loss exactly because I could hear people talking but could not understand what they were saying. I can remember my first hearing aid. It was purchased in a store about five blocks from campus. I tried the aid in the dealer’s store and was able to understand his speech much better with the hearing aid. I was also able to understand the time when dialing the operator on the phone. I thought I had found my cure.

However, after walking back to campus and entering the residence hall, I discovered that I still had a problem hearing what people were saying. Did the hearing aid break during my walk back to campus? It was my first experience in comparing a nice quiet office environment with the real outside world. I continued to use a hearing aid for almost 20 years but the benefits I obtained were related environmental sounds rather than a significant increase in comprehension.

The next cure I sought for my communication problems was to learn lipreading. It was my belief that all deaf persons could lipread. Since my grades in college were worsening, I decided that to drop out of college, take lipreading classes and work on the farm where my receptive communication needs were minimal. Cows and pigs do not talk and I was smart enough to get out of the way if they started running at me.

I am sure that most of you are aware of the difficulties with lipreading. You can only see about one-third of the sounds as they are said and many of them look alike. I was never able to learn lipreading well. I nominate myself as one of the worst lipreaders ever. The only sentence I lipread well is when people I have just met ask me “Can you read lips?” The reason I am able to understand that question is because I have been asked 1,001 times. In my speech Thursday night it was 1,000 times but last night I went out to a restaurant and it became 1,001.

My inability to lipread or receive substantial benefit from a hearing aid added to the negatives I had been emphasizing with deafness. Written communication was my only effective mode of receptive communication and few people were willing to use this method on a regular basis. I was telling myself “I

can not do this” over and over. Deafness was perceived as a stigma and I was developing a negative self-concept.

People who become deaf later in life often have a similar perspective and reaction. Deafness is viewed as a negative and there is a need to assist these individuals in dealing with these negatives and developing a more positive outlook for themselves. To paraphrase comments by I. King Jordan, President of Gallaudet University, while deafness may not be a positive thing, you can not allow it to become a negative thing.

It was almost two years after losing my hearing that I informed of services available to me and introduced to sign language. Information on vocational rehabilitation services was given to me by a social worker I met while going for an ear examination. My parents continued to be supportive and arranged for ear examinations to seek a reason for my hearing loss. I was fortunate to have an excellent VR counselor who provided me with information on almost all the postsecondary education options available to persons who are deaf. These options included Gallaudet College, National Technical Institute for the Deaf, an oral program in Utah, TVI in St. Paul, California State University Northridge and the Program for Hearing Impaired (PHI) at Northern Illinois University.

I chose to attend Gallaudet College because it offered the four year program I was seeking. I took an eight week sign language class to prepare myself for Gallaudet. As you can guess, this class did not prepare me for the receptive communication skills needed at Gallaudet. My signs were limited to “My name is S-T-E-V-E” and a few other simple sentences. Regardless of my inability to sign, I did recognize that sign language was much more effective for me than any other communication method I had tried except for writing. I was able to develop my sign skills during my three years at Gallaudet and now it is my preferred mode of communication.

Adjustments

Now, I would like to use my personal experiences to assist you in understanding the adjustments faced by deafened adults. 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 explain the emotions involved with hearing loss.

Emotional Responses

The emotional responses I have already discussed include denial and anger. I did not tell anyone I was deaf. Hearing loss is easy to hide and I did that for at least three years. Even today, I still hide my deafness and it is easy for me to do because I have good speech. I was also angry about the things I could no longer do, especially the loss of radio and listening to sports events. That caused a major change in my

social activities. The inability to carry on a casual conversation or to pick up the telephone and call a friend were aggravating. I was focusing on the negative and not looking for positive abilities.

If a deafened adult focuses on the negative, self-esteem will plummet and lead to feelings of depression and guilt. A person will always wonder if there was something he or she could have done differently to avoid becoming deaf. In the case of sudden onset, there are usually many "If" questions a person will ask themselves. In some cases, it is possible that deafness could have been avoided. However, it is not healthy to allow a person to dwell on the negative side of the situation.

Many deafened adults may view deafness as a temporary condition that can be cured by medication or surgery. I can remember my most frequent dream was that I was able to use the telephone. Looking back now, this dream represents my desire to be a hearing person. I no longer have that dream but I really can not tell you when I stopped having that dream. Since deafness is viewed as temporary, people prefer to hide it rather than acknowledge it publicly. The individual may display more anger-related emotions as it becomes obvious that deafness is not temporary (Larew, 1994).

Secondary Losses

Secondary losses refers to the impact hearing loss will have on the ability of the individual make adjustments for family, friends, work, and social activities. The deafened individual often is self-absorbed and not able to consider the impact their hearing loss has on others. The onset of deafness affects also impacts parents, spouses, siblings, children, and significant others. Having a deafened person in the family disrupts the established communication patterns and routines and 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.

As I stated earlier, I was fortunate to have a supportive family. Every member of my immediate family has taken at least one sign language class. They are not fluent but they can communicate simple messages to me if they choose. I do have to admit that I have never discussed all the issues I mentioned with my family because we are not able to communicate fluently in sign language.

I feel there may be a similarity between families of deafened adults and the families of deaf children. If the family decides to learn sign language, they frequently learn only basic survival signs or homemade signs. Families do not receive enough information to make decisions regarding available options and services.

Confusion of Identity

Adjustments relating to identity involve the deafened person realizing he or she can no longer function as a hearing person. Most deafened individuals retain their speech skills so they are able to

continue using speech. However, deafened individuals are aware of the lack of information they are receiving and, consequently, the need to develop alternative receptive communication skills. If the deafened person is introduced to other persons with hearing loss -- deaf, deafened or hard of hearing -- the individual becomes aware of groups of people who recognize their hearing loss and have adapted alternative methods of communication. Realizing this need for alternative communication and the fact that "I am no longer hearing" can cause confusion of identity.

Exposure to other persons with hearing loss assists deafened individuals in realizing they are not alone. They can explore social options available to them and possibly choose to become involved with other persons who have a hearing loss. The deafened person does not always make a choice between one group or another but, as all individuals tend to do, will gravitate to a group of people where they feel most comfortable. A change in social choices also impacts family members as discussed previously.

Acceptance

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.

Need for Competent Professional Assistance

The need for competent professional assistance is why I am talking with you today. Professionals in the field of deaf services need to be aware of the needs of deafened individuals. All too often, professionals recommend the person learn sign language and ignore the emotional adjustments I have discussed. It is important to understand that sign language is not the answer. Learning sign language can be helpful but it is not the answer.

Professionals need to understand the deafened individual is looking for a cure. Hearing aids, cochlear implants, and lipreading represent possible cures. As a professional, it is your responsibility to make the individual aware of these options, provide information on the pros and cons, and allow the individual to make his or her own choice.

Factors to Consider

When working with individuals who are deafened, there are five factors to consider. These factors are important with all individuals who are deaf but I will explain them as they relate to deafened individuals. The five factors are: age of onset, time elapsed since hearing loss, etiology of hearing loss, degree of hearing loss, and family reaction.

Age of onset is important as it relates to future plans. I could say that I was fortunate to become deaf at 18. I had not yet established myself in the work world and my future plans were still tentative. My hearing loss became a key factor as I developed my future career plans. People who become deaf later in life are not able to do this. If a person becomes deaf at age 30, having worked in a career area of 8-10 years, it would be very difficult to give up a job and go to college to learn new skills. There would be more adjustments needed if the person has family and other financial responsibilities.

The time elapsed since hearing loss is important because it will help you understand what stage of adjustment the individual may be experiencing. If the person has been deaf for several years and has received no assistance, it may take a longer time to develop a more positive attitude about hearing loss. If the hearing loss is very recent, then this individual may be denying the impact of hearing loss and looking for a sure cure.

Factors included with the etiology of hearing loss involve if the loss was gradual or sudden. Did the individual have time to prepare for loss of hearing or did it happen overnight due an accident, medical complications or other traumatic events. Several people I know became deaf due to neurofibromatosis (NF). This involves tumors on the acoustic nerve and also results in facial paralysis and other physical limitations. The trauma of NF or other disabilities must be considered when working with the individual.

The degree of loss has some impact on the individual's ability to benefit from amplification and their ability to continue to utilize speech for receptive communication. Many people who become deaf prefer to call themselves hard of hearing because there is less of a stigma involved. It is my opinion that individuals can label themselves as they prefer. I know several individuals who say they are hard of hearing but, in reality, they are deaf. I know my hearing loss is profound and my decibel loss is greater than many people who were born deaf. I called myself hard of hearing for several years even though I was only able to function at that level for two or three months.

Assessment of the family reaction allows the professional to determine what type of support system the deafened person has at home. As previously discussed, the impact of becoming deaf is not limited to the deafened individual alone. If a study was done, I think that the responses of families including deafened individuals would be very similar to those of parents of deaf children. Only a small number of families learn sign language and other communication options are often used. I am willing to bet that the deafened person often feels very isolated during family activities.

Personally, I was very fortunate to have a supportive family. I would not be speaking here today if they had not encouraged me to continue my education and supported my decision to learn sign language. My parents also provided financial support when needed. No one in my family is highly skilled at sign

language but they have taken sign language classes and utilize fingerspelling and simple signs when needed.

Working with Deafened College Students

When beginning to work with deafened college students, it is important to answer two questions: “How does the individual communicate most comfortably and effectively?” and “What are the goals of the student?”. If the individual is recently deafened, there is also the question of how to counsel a person who has no effective method of receptive communication.

Communication

For reasons already discussed, many deafened individuals are not skilled at lipreading. They may be able to use lipreading to communicate in one-to-one situations but would not be able to understand in a classroom setting. Based on their experience with conversations in different situations, deafened people may be more adept at anticipating questions or comments to assist with their lipreading skills.

Written communication is often effective with deafened individuals but the process is time consuming. When using written communication, phrases can often be used instead of complete sentences to save time. College personnel need to be aware of the need for written communication. Deafened people are similar to other persons with hearing loss in that they do not always admit they do not understand.

For classroom communication, use of voice to text translation is more effective than use of a sign language interpreter. Most deafened people are not skilled in American Sign Language (ASL). If they have learned sign language, it is often a form Signed English. Since English is likely to be the individual's first language, it is often easier to learn Signed English. It is essential that professionals understand that learning sign language is not the answer for resolving all the issues and adjustments faced by deafened individuals. It takes time for a person to acquire sign language skills, and frequently, the deafened individual does not have the opportunity to practice and develop receptive sign language skill levels needed to be effective in the classroom environment.

There are two different methods of providing voice to text translation. One is using computer aided realtime translation (CART) which involves hiring a court reporter who has the computer technology to convert their shorthand to text. This accommodation is often expensive, with fees ranging from \$60-150/hour, depending on the court reporter and the location. Not all court reporters have the training or technology available to provide realtime captioning services. The National Court Reporters Association has developed a national certification test for realtime translation. Persons achieving this certification are able to translate materials at the speed of 180-200 words per minute with 96% accuracy or better. There are approximately 300 reporters who have the Certified Realtime Reporter (CRR) certification so availability is an issue. This situation is similar the existing problem with sign language interpreters in that there are many court reporters who do realtime translation but do not have national certification. Persons who want a list of certified reporters should contact the National Court Reporters Association.

Another form of voice to text translation involves hiring a typist and using a laptop computer. This method is less costly but also less effective as few typists are able to keep up with the normal rate of speech. Information is often missed so the student may not be full aware of topics discussed in the classroom. This shortage of information must be addressed and resolved.

Goals

It is important to be aware of the goals of the deafened student in attending college. The goal may be to learn a new career or to develop skills to continue current employment with different responsibilities. Deafened individuals may choose to learn a new career because of the communication demands in their job prior to becoming deaf. Some jobs, such as telephone operator, obviously require a career change. The Americans with Disabilities Act (ADA) and Section 504 of the Rehabilitation Act of 1973 provide a method for deafened individuals to retain their employment using reasonable accommodation. However, many deafened individuals are not aware of assistive devices such as TTYs, flashing signal devices, CART and other devices available that can provide accommodation.

The deafened individual may be able to continue to perform the job with accommodation but the communication demands are stressful. The individual may choose to pursue a different career where receptive communication is not as demanding. The person may also be seeking a change in environment. Staying in a job where you can no longer communicate with your co-workers can create stress, so moving to a new environment is seen as a way of relieving stress.

When advising the deafened student, it is important to discuss the communication demands of the chosen field and how the student may be able to cope with these demands. The student may need assistance in identifying career areas where his or her skills may be used but the amount of personal communication involved is minimal.

Conclusion

Assisting the deafened student at the postsecondary level requires an understanding of the adjustments that are facing the student. Of primary importance is assisting the student to develop receptive communication skills. The student should be informed of the communication options and allowed to choose the method they prefer. Exposure to other persons who are deaf, deafened, or hard of hearing is also beneficial. It allows the student to know they are not alone in dealing with hearing loss.