

Students with Acquired Hearing Loss – Huh?

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Abstract

Students who acquire a severe to profound hearing loss face a difficult adjustment psychologically, socially, and vocationally. They frequently are unaware of other deaf or deafened people and the services available to them. Communication is the first issue a deafened student must address. This paper provides a description of adjustments experienced by deafened adults (Zieziula & Meadows, 1992), as applied to the personal experiences of the presenters.

Students with Acquired Hearing Loss – Huh?

We would like to open with the following definition from the Devil's Dictionary, 1991 ALDACon version, written by Karen Graham. ALDA is the acronym for Association of Late Deafened Adults.

Huh? - The most utilized word in the ALDA vocabulary. It can be interspersed anywhere in a sentence. Often means: "Rephrase the question, please." May also mean: "I don't sign," or "I don't read lips," or "Even if I could understand you, I wouldn't know what you're talking about."

This definition was written to be humorous. We wanted to start with this definition because it is important to understand that deafened students often do not have effective receptive communication, especially if the hearing loss is recent.

The loss of receptive communication is one of the most difficult losses for an individual to encounter. When an individual is no longer able to listen to the radio, use a regular telephone, or have

casual conversation with friends, family, and children or grandchildren, the psychological impact is enormous. People who are born with hearing loss do not have to make adjustments in communication as deafened persons do.

In this presentation, we will explain the impact of being deafened from two perspectives. My experience involves sudden onset hearing loss as a young college student who is male and single. Mary will provide her perspective with progressive hearing loss as a married female with children.

Persons who acquire a severe to profound hearing loss frequently are unaware of other deaf or deafened people. Deafened individuals tend to experience difficulty at work, withdraw from social events, and suffer inwardly as a result of the loss of receptive communication.

Communication is the first issue a deafened individual must address. The myths and realities of lipreading, hearing aids, and other assistive listening devices must be addressed. Sign language is an option but it does take time to learn. Professionals who work in the field of deaf services often see learning sign language as "the answer" to problems encountered by deafened individuals. It is important that professionals understand that sign language may be part of the solution but, by itself, is not the solution for deafened individuals. Psychological issues need to be addressed and coping skills need to be developed.

Zieziula and Meadows (1992) developed a series of adjustment themes based on their study with deafened adults. We will discuss these themes based on our own personal experiences and hope that you can apply these experiences to

situations you encounter. The five stages of adjustment as identified are:

- Spectrum of Emotional Responses
- Secondary Losses
- Confusion of Identity
- Acceptance
- Need for Competent Professional Assistance

Steve Larew: The spectrum of emotional responses includes disbelief, shock, anger, guilt, and other emotions. I became deaf at age 18 years due to a viral infection and high fever. For approximately one week, I recall having a “bad cold” with runny nose, cough, sore throat, headache, and other related symptoms. I did not go to a doctor but chose to drink lots of juice and use aspirin. While having this cold, I noticed some difficulty hearing but assumed it was related to the head cold. One week later, the cold was gone, but I was still having difficulty hearing. I thought my radio was broken, the TV in the lounge seemed to be broken, and other students were mumbling. I refused to believe that I could not hear. I chose to become more isolated and less involved with student events.

I was angry that I had become deaf and felt guilty about not going to the doctor while sick and possibly not taking care of myself. The only other person I had met who was deaf was almost 90 years old. It is okay to be deaf if you are 90, but it was not okay to be deaf while I was 18! I had never met another young person who was deaf and had no idea of services available.

Mary Clark: My hearing loss was different than Steve’s as it was a gradual loss. Interestingly enough, individuals who experience a gradual loss also go through a spectrum of emotional responses. Each time the loss is experienced, we go through the emotions again. Despite my hearing loss, I was able to function as a hearing person until thirteen years ago after the birth of my second child. I was first diagnosed with a hearing loss in tenth grade. From tenth grade until my senior year of college, I did pretty well. In my senior year of college, I went from a 45 db loss to a 75 db loss and was labeled “legally deaf” a few months before I graduated. I was scared but still was not addressing grief issues and remained very positive. This may have been due to how I was raised. I still used the telephone, used hearing aids well, and

did not know other people with hearing loss. I had majored in an oral Deaf Education program at Ball State University, so that fit in with my hearing loss.

The entire time I was at Ball State, I was unaware that there was a disability coordinator who could have assisted me and that services were available. I finally told a professor about the hearing loss when I felt I was starting to go through some depression, and she helped me greatly by just talking with me and letting me know my feelings of sadness were very normal. She supported me by coming with me to the speech and language clinic to have my hearing tested. It was very comforting to have a “friend” or someone who supported me through this time, and I think this is important for those students like me who are enrolled in a regular college curriculum. I also had severe vertigo at various times during my college years. I knew it was related to my hearing loss, but I kept it to my myself and suffered through it. I was unaware there was medication that would have helped had I gone to a health center or a doctor. The vertigo was very depressing.

After the birth of my second child, I lost all the hearing I had left within a sixteen month time period. I went through these emotional responses once again and to a much greater degree.

Steve Larew: Secondary losses include relationships, social and work activities, and loss of environmental cues. Having become deaf, it was difficult to maintain friendships I had developed during the first semester of college as well as friendships from high school years. Using the telephone to stay in touch was out of the question. This was 1971 so the technology was not available to assist as it is in the year 2000. E-mail, TTYs, and pagers would have eased distant communication. Face to face communication would have remained difficult.

I became more of a “loner” and did not involve myself in college activities. My grades began to decline as I was not able to hear class discussion or lectures. I had always been dependent on auditory senses for learning, and now it was necessary to depend on visual skills and reading. I had a hard time making this adjustment.

Mary Clark: I had the same problems with friendships when I became deaf. I was the only student I knew of at Ball State that had a hearing loss. My closest girlfriends were supportive, but I felt very

different from everyone wearing the hearing aids and having a hard time at social events. I could still do a lot of “hearing” things like talk on the phone and talk one on one with friends, but going to a party or something was difficult.

Dating was hard. I never told my dates I wore hearing aids and if I couldn't hear, I would bluff. I remember the hearing aids, used to have feedback noise if I hugged anyone, so I was always careful not to do that. I never dated anyone with a hearing loss because I did not know of anyone with a hearing loss. My world was all hearing friends and family members so I just dealt with the situation I was in the best I could. In noisy places I learned how to sit next to the person so that my “good” ear was closest to the sound. If it was noisy, I sat in the noisiest area and turned down my aids a bit. I found this to be helpful as others would have to speak up a little louder due to the noise, and the hearing aids would not pick up the background noise but pick up the people close to me talking loudly. Regardless, it was not really fun to go out and try to meet and talk with people. It was more of an anxious situation.

The way family get-togethers used to be and the way they became after my hearing loss was another secondary loss for me. My family is the kind of family where dinner time is a ritual that involves sitting at the table having lively discussions for hours on end. It was and still is a very tiring situation to continue to do this, as much as I enjoy being with them.

Confusion of identity involves deciding which social group an individual is comfortable with. At first, the deafened individual only knows he or she cannot hear. The person is not always aware of the Deaf, deafened, or hard of hearing organizations and groups. Once the individual is aware of these groups, the person needs to decide which is most comfortable. The individual is not limited to being involved in only one group but, most often, will find a higher comfort level with a certain group and become more involved with that group.

Steve Larew: My personal experience involved meeting Deaf people at Gallaudet College (now University). When I first arrived at Gallaudet, I had taken a six-week sign language class. My sign skills were basically limited to “My name is S-t-e-v-e”. Obviously that was not enough to interact

with 900 of the 1,000 students at Gallaudet who were fluent in American Sign Language.

I learned at Gallaudet that sign language was my most effective method of receptive communication. Hearing aids did not increase my speech comprehension.

My lipreading skills were and still are mediocre. Sign language worked for me. It was awkward for the first year, but I became friends with people who were patient with me. I use Signed English rather than American Sign Language (ASL) but people are able to understand me, and I understand them most of the time.

While I was a “think hearing” person at Gallaudet, I became more comfortable with Deaf groups than hearing groups. I was never able to fit in with hard of hearing groups. In 1990, I became involved with the Association of Late-Deafened Adults (ALDA) and found a group with whom I felt more comfortable than Deaf people. In simple terms, I found I identified with a group of people who were my peers and who had similar experiences.

Some of these deafened friends also attended Gallaudet at the same time I was there. At that time, in the mid 1970's, we did not really discuss our onset hearing loss. If we did, it was not a lengthy conversation because I have no recall of those discussions. There were attempts to set up deafened groups before ALDA was established, but none of them had the success of ALDA. Now many ALDA members go to professional or consumer conferences, and we have become a clique. You can usually find us sitting at a table in the corner of a bar using our basic sign language skills and other modes of communication.

Mary Clark: Since my hearing loss was progressive, my family had some time to adjust in their own way. Through high school and college, I was identified by my family as a person with a “little bit of a hearing loss.” I described myself this way until 13 years ago. In college this was not really an issue because there was no real need for me to identify myself with regard to my hearing loss. I didn't talk to people about it.

My crisis with identification happened after I became functionally deaf. I was taking my three-year-old daughter to day care one morning it hit me that I was no longer a person with a “little bit of a hearing loss.” Lauren was sitting in the back of the car and said something to me.

Normally, I would have heard her, but I could not understand her that day. I tried to bluff and she started crying. I bluffed the other way and she became hysterical. I then said, “we will wait until tonight and ask Daddy to help us” and that did not work either. She was hysterical and I had no idea what she was saying and could not fix it. It was a moment I will never forget, I asked another mother to tell me what my own child was saying. I realized I had to swallow my pride and do that for her sake. I then went out to the car, smiling and waving bye after we got it resolved, and then I fell apart. I realized I was not going to be able to hear her again and I had to figure out how to fix it. That night, as I was tucking her in, I told her that my ears were broken inside where she could not see them, and I could not hear her anymore but that things would be ok. We hugged and cried a bit. I think that episode had to happen for us to accept the fact that I could no longer hear.

Steve Larew: Acceptance involves not only accepting hearing loss for oneself, but acceptance by family and significant others as well. This acceptance involves identifying an effective method of communication. When an individual can understand other individuals, the road to acceptance is smoother. The individual learns how to function at home, at work, and in social situations.

I have met other deafened persons with family members who are not able to adjust. This is a difficult situation.

Assistive technology makes acceptance easier. TTYs, fax machines, visual alert devices, close-captioned television, Communication Access Real-time Translation (CART) and other devices makes communication much more accessible. Deafened individuals are very interested in cochlear implants. The improved technology with implants offers a cure to hearing loss that was not available in past years.

Mary Clark: I want to a comment about family members being able to adjust. This is crucial to late-deafened persons adjusting themselves. If there is no support system, he or she is not going to accept himself/herself because no one else is accepting them. At Hearing Loss Link, one of the things we try to do is get family members or friends into a workshop or counseling with the deafened person and teach them about grief and

loss and help them develop coping and communication strategies.

Students need this kind of support system when they go home or when they are at school so that there is a feeling of some kind of control and respect for who they are, regardless of the hearing loss issues.

Steve Larew: The need for competent professional assistance involves you people in the audience as well as speech, hearing, and medical personnel. I can still remember my first visit to an Otolaryngologist in 1971. He could not find anything wrong with my ears so he asked if I was worried about the military draft, implying that maybe I was psychologically deaf. He then asked if I had been smoking bad marijuana! There was no useful information provided.

My parents were determined to find a cause for my hearing loss. I went to the hospital and other sites for numerous hearing tests and examinations. It was approximately one year later we met a social worker who informed us about vocational rehabilitation. I met with this counselor who informed me about Gallaudet, National Technical Institute for the Deaf (NTID), and a few other programs. In 1971, there were not many options available.

I chose to attend Gallaudet, learned sign language, and later decided to pursue a master's degree in Deaf Rehabilitation Counseling at Northern Illinois University. Graduate courses in counseling and audiology helped me to learn about myself. However, it was aggravating that I had to wait ten years to learn that my experiences were normal reactions.

It is important for service providers to be aware of the resources available for deafened persons. Effective therapy involves identifying an effective method of communication. How can you assist an individual if you cannot communicate? Use of text communication is important. With the widespread use of computers, it should not be too difficult for the therapist to type rather than use sign language or speak.

The number of resources available to assist deafened individuals is growing. The Association of Late-Deafened Adults (ALDA) hosts an annual conference. In Illinois, Hearing Loss Link is available to provide assistance to deafened persons in the Chicago area and can provide technical assistance to professionals across the country.

Mary Clark: Steve and I give presentations for people who work with students and it is obvious that students need to know about the disability coordinator, and the disability coordinator needs to know how to provide support for late deafened students. I think an in-service for ALL staff is vital, considering so many late-deafened students are in regular college curriculums and like I was then - probably not talking about it. Most late-deafened people are not assertive or do not know what kind of help they need.

At the Hearing Loss Link, we begin with communication. For me to tell clients to learn sign language when they have no one who signs to them is obviously not going to help their situation. Consumers and students tend to come to the Link through family members or because another crisis has happened. We use a laptop or listening device to help the person understand. The first time we see them we practice, and we have to be the communication specialist because the individual may not be able to address what is needed for communication. We try to include them in

social events or a support group that deals with acquired hearing loss. It would be beneficial to students to hook them up with another late-deafened person who lost their hearing as a student themselves. To hook them up with other students with hearing loss would be ideal.

In addition to what Steve said about resources, we have some books that ALDA sells—an ALDA reader and conference proceedings. They are helpful to lend out to consumers with acquired hearing loss issues and are helpful to professionals that deal with this population group.

Resources

Zieziula, F. R. & Meadows, K. (1992) The experience of loss and grief among late-deafened people: a report on research and theory In S. Larew, K. Saura, & D. Watson (Eds), *Facing Deafness*, (pp 58-63). DeKalb, IL: Northern Illinois University Research and Training Center on Traditionally Underserved Persons Who are Deaf.