

Linking Up with Deafened Students

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Abstract

A survey of current members of the Association of Late-Deafened Adults (ALDA) shows that 33% of the members lost their hearing before 20 years of age. This workshop focuses on strategies to be used when working with students who have acquired hearing loss and hard of hearing students who may be experiencing a progressive hearing loss. Emphasis will be placed on communication, identity, and career counseling issues.



Introduction

Mary Clark:

We will be talking about late-deafened students this morning. I want to start by providing a definition of late-deafness. Late-deafness means we are talking about people who become deaf after they have acquired speech and language and have grown up in a hearing world. A significant aspect of becoming late-deafened involves the transition from the hearing world to the deaf world.

I attended Ball State University. Richard Harris told me earlier about the disability office at Ball State that was set up in 1973. I started in 1974 and I was never referred to that office. It seems that many late-deafened individuals are not referred to these offices for support services.

Steve Larew:

I became deaf during my first year of college. That was a very frustrating time for me. What we are going to try to do today is provide you with information about our personal experiences and how you can use this information to provide appropriate services to deafened students in your college program.

Factors to Consider

When you are serving people who are deaf, deafened, or hard of hearing, there are five factors to consider. These five factors are age of onset, time elapsed since hearing loss, etiology of hearing loss, degree of hearing loss, and family reaction.

We will talk specifically about people who are late-deafened. How old were they when they became deaf? I was 18. Mary was hard of hearing growing up and became profoundly deaf later in life. The age you become deaf is a factor, but so is the time since the person has become deaf or started to notice that they have a hearing loss.

I was 21 before I was informed about services available to me. I went through three years of "communication hell" due to my lack of receptive communication. I tried different methods, but nothing worked. Maybe you are working with an elderly person who is coming back to college because he or she recently became deaf. Maybe you are working with people who have been deaf all their life, learned about services, and want to go to college.

Another factor is the etiology of the loss. For myself, it was sudden. I became sick with what I thought was a bad cold. I noticed during that time I couldn't hear well and blamed it on the cold. Maybe I could have become healthy if I had gone to the doctor and received the right medication. Ten days later, the cold was gone but my hearing stayed gone, too. I went from having regular hearing to having a 70-75 dB hearing loss in two weeks.

How severe is the person's hearing loss? The decibel level does not tell you a lot about their communication skills because different factors are involved with communication. Is the person able to benefit from assistive listening devices?

The last factor to consider is the family reaction to the person becoming deaf. I consider myself lucky because my parents were supportive. It was through the persistence of my parents that I finally found more information about services from Vocational Rehabilitation (VR). I learned about Gallaudet, NTID, and other college options. If I had been by myself, I probably would still be in Iowa working on the farm. Since it was their goal for me to attend college, the mission was accomplished.

Stages of Adjustment

Frank Zieziula and Katharine Meadows from Gallaudet University identified five different adjustment stages for persons with acquired hearing loss: spectrum of emotional responses, secondary losses, confusion of identity, acceptance, and competent professional assistance (Zieziula & Meadows, 1992). These stages were based on analysis of interviews with a group of deafened individuals.

The first stage is the spectrum of emotional responses. My first response was, "Why me?" A person who has just become deaf is not ready to admit it, especially a younger person who is becoming deaf. When you are a teenager, you have an active social life. It's supposed to be an exciting time for you. You do not think about yourself as disabled in any way. My experience was that only elderly people become deaf. When you are 65 or 70, it's okay to be deaf. When you are 18, it's not okay to be deaf. It's important to understand that with younger college students, it's not easy to admit that they have become deaf.

Denial is a basic emotion. This was a temporary ten-day hearing loss. The cold was gone and my hearing would come back. That was not reality, but it was my thinking at that time. You have to understand the emotions a person is experiencing. It is important to know when they started to have their hearing loss. How long had this person been living with this? I have met people that have been deaf for 15 or 20 years, and don't admit it. They prefer the term "hard of hearing" but functionally they are deaf. They fake it. I faked it for three years. It is an easy thing to do, and I still do it.

I stayed in college for one year after my hearing loss. I had nine or ten classes during that time. I told only one teacher that I was deaf. The reason I told that teacher was because I didn't know when a term paper was due. At the end of one class, everybody else in the room walked up to the front of the room and put a paper on the desk. I had no paper. I had to tell that teacher about my deafness because I did not want to fail the class. Fortunately, he was very considerate, and let me finish the paper over the weekend.

Mary Clark:

The second stage is secondary losses associated with acquired hearing loss. One issue to address is the loss of self-esteem. Acquired hearing loss starts to eat away at you and makes you feel incapable. My hearing loss started in about tenth grade when I received my first hearing aid. They discovered I was deaf in one ear, and the other ear had a moderate loss. I wore a bi-cross aid, but did my best to try to hide it. My hair was perfect every day in college because I did not want to be known as a person with a hearing aid.

I went to Ball State University without telling them about my hearing loss. My first major was the teacher-training program to work with children with mental retardation. I later switched to deaf education. You would think a person with a hearing loss would be mentally healthy in a deaf education program, but I was not. I still had a hard time with my self-esteem.

My friends were people in the deaf education program who understood deafness. That was really good for me. Ball State had a very oral philosophy, which I thought was really good in terms of my own situation. It fit right in with my personality, but it really affected what I was learning or not learning. People go to college to get information. In reality, I was sitting in class not getting the information.

There was also the dating experience in college. People say that's the place to meet your future husband. When I met guys, there was a problem because I did not know how to bring up the fact that I had a hearing loss. Every time I would put my head on someone's shoulder, the hearing aid would make strange noises and create a lot of feedback. Because I had not told the person about hearing loss, my date would look at me strangely and say, "What the heck is that?" There were a lot of issues at that time, and those types of experiences just made my self-esteem regress further.

Steve Larew:

I grew up relating with hearing people. The sign "think hearing" has many different meanings in ASL. I translate that literally and I thought as a hearing person. I decided to attend Gallaudet College. During a six-week sign language class, I learned to sign, "My name is 'S-T-E-V-E'." I arrived at Gallaudet. Any of you who have visited Gallaudet know that you can't survive signing, "My name is 'S-T-E-V-E'." I learned that the deaf students there had different behaviors and different experiences than I had as a hearing youth.

Where did I fit in? It's hard to fit in when you can't communicate. One-on-one, deaf people are very nice. They will sign slowly and understand you are learning sign language. But when the second, third, and fourth people join that group, it's back to ASL, and the deafened person is lost.

Sometimes you try to go to a hard of hearing or hearing groups and one-on-one communication, again, is fine. The people speak slowly, but then you get into large group situations, and people go back talking at their regular speed.

Deaf, hearing, hard of hearing, deafened – where do I identify myself? Where do you feel most comfortable? For myself, I went through Gallaudet and then graduate school. I was starting to feel comfortable as a deaf person. Later, I learned about a self-help group for people who become deaf. That group became the Association of Late

Deafened Adults (ALDA). Luckily for me, three years later I met the people involved, and I identified with those people that became deaf.

I identified with their communication skills and struggles trying to learn sign language. There is no doubt in my mind that I identify best with people that are deafened. I still identify with people that are deaf or hard of hearing, and I still interact with people who are hearing, but I best identify with people who are deafened. You don't have to choose one group, but you decide where you feel most comfortable.

Mary Clark:

Steve's loss was very sudden. Mine was very progressive. We both had to go through the same stages to where you can accept the loss. You have to go through a hard time. I had a good experience in college in that I became good friends with a professor. She was very instrumental in helping me through that transition of feeling bad. People were telling me I should not feel bad about this, but I found that it was ok to feel bad about it. I had to go through that process to actually accept the hearing loss. I went to this teacher and talked to her about the hearing loss. I feel fortunate because I knew people that understood deafness. I went to this professor and said, "You know, I can't hear the alarm clock anymore." It was a real loss to not be able to hear the alarm clock. When I went to this professor, she sat down with me and told me it was okay to be scared, and it was okay to feel bad about it.

Going through those stages was very important. You do that if your loss is sudden or if it's progressive. My hearing loss went from 45 dB all the way to 110 dB within 10 years. Every time I lost more hearing, my functional level changed. Every time my functional level changed, I went through the grief process again. People would wonder why I was depressed if I already had a hearing loss. The functional level of not hearing something, like the alarm clock or your children's voices, would change. Students need a mentor who can help them during these transitions.

I'm director of an agency called Hearing Loss Link. We have students come in and talk about problems that are unrelated to academic situations. They mention they have a hard time going to class because they are so overwhelmed with relationship problems. It is helpful to have counseling services for these students because their issues may actually be a combination of many things. Sometimes people never get past the depression stage. Students may go back to the denial stage and say they that they are fine and don't need counseling. In actuality they are still depressed. You have to consider that if you have students who are deafened.

Steve Larew:

The fifth theme is competent professional assistance. When I became deaf, I met many professionals in the field of medicine and audiology, but they didn't give me the help that I needed. I was told one time that maybe it was a back problem and went to a chiropractor for two months. He thought he could adjust my back and I would become a hearing person again. I was looking for a cure, and there are some professionals out there that take advantage of that.

I remember my first visit to an otologist. He couldn't figure out why I became deaf and asked my parents if I could be psychologically deaf. I was 18 and, in 1970, you had to worry about the military draft lottery. My draft number was high enough that I was not worried about it. I'll be honest and admit that going into the Army was not something I wanted to do but I'm obviously not psychologically deaf. He also asked me if I was smoking bad marijuana, but I was not involved with pot, drugs, or anything. This was my first exposure with a professional person and I was asked these types of questions. Overall, it was a negative experience.

I also experienced what I call communication myths. The first myth is related to hearing aids. I thought that buying a hearing aid would solve my problem, and I would become a hearing person again. I went to the hearing aid dealer, and he gave me a hearing aid. When he talked to me, I understood him much better. After driving five blocks

back to the college campus, something must have happened because the hearing aid didn't work when I arrived at the dorm. I couldn't understand anybody. I couldn't understand the speech of people in the dorm or the teachers in the classroom.

Looking back, I realize how quiet that store was and how slowly that dealer was speaking. He knew what it took for people to understand better. The hearing aid made me more aware of environmental cues, but never improved my speech comprehension enough that I could function comfortably in a social environment.

The hearing aid did not work! I took lipreading classes because everybody knows that all deaf people can lipread. That was my attitude. I took two or three different classes, but failed them. I've never been able to learn that skill.

Actually, I can lipread one sentence. The first thing people ask me when I tell them I'm deaf is, "Can you read lips?" My answer is "no," but they don't believe me because I understood that one question. I have to explain in more detail. If you meet hearing people on the street, more than 50 percent of them believe those myths about hearing aids and lipreading. Even people who become deaf have those beliefs.

Communication Issues

The communication system that usually works best for deafened students is computer aided real-time translation (CART). Many people don't know about it. It's expensive, but so are many quality services. It doesn't matter if it's interpreters or captioning, you have to pay the going rate.

Before CART was developed, ALDA would hire typists and ask them to type on a computer for people to read. The problem with that is it's a lot slower. People can speak 150 words a minute. How many people can type 150 words a minute? Sometimes that will work in the classroom, but it depends on the class.

Many deafened people like the idea of cued speech. Some people say it's easier to learn than sign language. I don't know if that's true, but people need to know the options available for them.

We often assume that people know what services and assistive equipment is available for people who become deaf. Many people stay isolated or stay at home. They don't seek the assistance they need because they don't know about it. They have never seen a TTY or other assistive devices. They need to see, learn, and experience. A deafened person needs information about the various communication options and assistive equipment available.

Mary Clark:

It is not always a good thing to encourage students to learn sign language. Those who will be part of the deaf program, have contact with other deaf students, or choose to use it as a communication method may use it as a tool for communication if they learn it well enough. However, I'm not sure if that will work for them if their world is hearing, they attend a hearing college, and have hearing family and friends.

Resources

Now I'm going to talk a bit about resources. I'm wearing some different hats today. The first hat I'll wear is the ALDA hat. We will have our tenth conference this year, September 2-6 in Chicago. ALDA does not provide direct services, but serves as a support. ALDA has a newsletter, an annual conference, and chapters all over the country. It is a perfect resource for those that are late-deafened. If you know of students who are late-deafened, you may want to encourage them to get in touch with ALDA and attend the conference this year.

My second hat I'm wearing is my Hearing Loss Link hat. Hearing Loss Link started about four years ago and is a direct service agency in the Chicago area. We offer *CARE* services – counseling, advocacy, referral and education

services. We also offer survival sign language classes. I mentioned earlier that it's not necessarily a good thing to send late-deafened people to sign language classes. In the classes we offer, we ask late-deafened individuals to bring someone to the class with them, perhaps a parent, someone in the family, a friend, or co-worker.

We also do vocational work. If you consider employment and changing employment, this is a big issue for people with acquired hearing loss. We have many clients who come in who are in an employment situation, but are not sure if they can stay there because they have lost their hearing. Hearing Loss Link provides support for them and works to educate employers regarding their employees who have a hearing loss. As we mentioned earlier, students do not necessarily know what kind of technology is available. The same thing is true with adults in employment situations.

Hearing Loss Link offers a support group, as do ALDA chapters around the country, which can be of benefit to individuals with acquired hearing loss. We sit and have a structured situation where people can talk about how they feel and cope with various things. There are rules; no cross talk or judging is allowed. It is structured so that people can share their experiences, work through things, and at the same time, meet others like themselves.



References

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