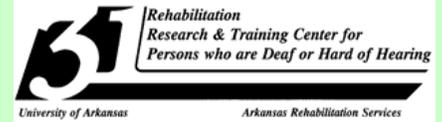




Selected Proceedings of ALDAcon 2004 “Green Mountain Odyssey”



GET THINGS DONE WITH ALDA ADVOCACY Cheryl Heppner

Cheryl Heppner: We want you to learn a little bit about what ALDA is doing in advocacy. We also want to hear from you: what experiences you have had, what questions you have, any problems you haven't been able to solve, and collectively help each other. We have two panelists who will talk about ALDA advocacy.

The ALDA advocacy list serve was set up to make a core committee of people who want to work on advocacy at the national level. It's meant to be for people who will actively be involved, not just talk. It also can be a good group for discussion of things that are happening to you in your community. And we can help you try to solve those problems. I hope you will consider joining the ALDA advocacy group. If you have e-mail, you can be a member.

First, I want to give you some stories from people who have actually solved problems in different areas that required advocacy. I'm going to ask Brenda Estes to come up first and talk about her experiences.

Brenda: In 1999, I was diagnosed with Meniere's disease and I was working in a hospital in Virginia. The next couple of years, my hearing became worse to the point where I had to ask for a portable amplifier. It's a portable battery-operated amplifier that you can attach to your telephone. It cost \$19.95. My employer refused to pay that much, but didn't think twice about paying \$90.00 for eight portables heaters to be located throughout the common, or \$40.00 to \$60.00 dollars for oscillating fans throughout the department. My \$19.95 was cheap, but they didn't want to pay for it.

As my hearing declined, my co-workers got tired of me asking them to please look at me when they talk, so I could lip read them. Or, if necessary, to write down on paper what they were saying. At the staff meetings, I was ordered by my director and my supervisor to sit in front of them so I could lip read them while they conducted the office meeting.

At one point in time, the manager from human resources came to our department to talk about benefits. During that meeting, I asked her point-blank, in front of 35 co-workers, what happens to me when my hearing become worse? The manager of human

resources told me that I would then be asked to leave the hospital. I could either go on long-term disability or resign, but that I could not stay there! What a response! She tried to tell me that I was the only employee with a hearing loss in an organization of over three thousand employees, and I know that was not true. Several months later, I was demoted down to the bottom of the ladder. As a result, my salary was frozen for years to come. My salary was cut to be not much higher than a file clerk. I was devastated. How was I going to provide a living for my son and me? How was I going to pay for his college education?

My director announced my demotion at an impromptu staff meeting. She made it clear that it was from my hearing loss and had nothing to do with the quality of my work. It was one of the most humiliating, devastating experiences of my life. I wanted to run and hide, but I couldn't because my son was depending on me to be there for him. My audiologist noticed I was becoming depressed and asked me if I wanted to talk. She immediately referred me to the Northern Virginia Resource Center and to the Gallaudet University Law Center. She assured me that both places would be able to provide me with ADA information, and that, perhaps, Gallaudet University could file my ADA complaint for me. I remembered seeing something on the news in the past about the ADA, but I had absolutely no idea how the ADA could help someone like me—someone with a hearing loss.

Northern Virginia Resource Center provided me with lots of ADA information and assisted with my call to Gallaudet University to meet with one of their attorneys. While waiting for information from the ADA, I felt something wet against my hand. I looked down and saw a golden retriever nudging my hand, with a banana peel in her mouth. I had just met Dana, Cheryl Heppner's former hearing dog. I fell in love with Dana and looked for her wherever I went—especially on my visits to the Northern Virginia Resource Center. I left there that day overwhelmed with all this information about the ADA, and thinking that maybe I could get my old job back. At Gallaudet University, I met with the attorney to discuss and file my complaint against the hospital. They asked me to document my discrimination, and I learned that I should have started documenting from day one. It's very important that you document right then and there of discrimination. Don't think, oh, I will give them another chance, maybe I misunderstood. Write it down while it's still fresh in your mind. I was fortunate that, even though I did not start documenting from day one, I had enough documentation and memos and e-mails to win my case.

Over the course of the next five months, I had numerous conversations with my attorney. She asked me to make a wish list of accommodations that I felt that I would need in my job. This was a very extensive list, because I worked out of two offices. Plus, I have a small work station at one of the nurse's stations. So if I needed a TTY in one office, I also needed it in the second office and at the nurse's station. Whatever I needed at one place, I needed at all three. I had done a lot of research on the Internet, looking for information and assistive technology. I could have saved a lot of time if I had just contacted the Northern Virginia Resource Center. So, if you have a resource center in your area that's devoted to advocating for deaf and hard of hearing people, utilize them. Some areas have a center for independent living that may be able to provide you

with some information also.

At one point, we had a consultant from vocational rehab come to the office to do an assessment. She was amazed at how noisy the environment was and wondered how I had worked there for so long and been able to cope in such a noisy environment. I think we all do that, because we don't want to create problems or situations, and we want to avoid confrontation. But if you don't do anything about it, it's never going to change. I stood up to them and I won. I felt even more empowered when, several months later, the manager and the director of the human resource department told me that they were afraid all along that I was going to go public. At that moment in time I thought to myself, "Why in the hell would I go public about one of the most humiliating and devastating experiences in my life?" It took a few years before I realized the answer. Public awareness.

I would like to summarize real quick the results of my Title I employment discrimination complaint. I was reinstated into my old position, the demotion was removed from my personnel file, and, best of all, my salary was unfrozen. The hospital spent thousands of dollars providing accommodations, including paying the attorney's fees. They didn't want to pay that \$19.95 for a portable battery-operated amplifier, and ended up spending over \$5,000 in equipment, not counting the attorney's fees. They were legally required to provide CART for hospital-wide management meetings and training. They provided me with scripts for hospital-wide mandatory in-service videotapes, with the understanding that they would be closed captioned in the immediate future.

When you file a discrimination complaint, you have 180 days from the date of the discrimination to file a complaint. That deadline is extended to 300 days if the charge also was covered by a state or local anti-discrimination law. To file a Title I employment discrimination, in regard to the equal employment opportunity commission (EEOC), please do not go to your local human rights office. They are not qualified to help those of us with a hearing loss with our discrimination complaint. When I filed my second discrimination complaint four years later, I had five different case workers in 15 months. Don't go to the human rights office; go to EEOC.

If your employer or supervisor requests a meeting with you after you had notified them of or served them with a discrimination complaint, do not meet with them. Contact your attorney or EEOC immediately. Only meet with your director or human resource person after you have been given the go ahead by your attorney or EEOC, not before. Should your employer or co-workers contact you, get in touch with your EEOC or attorney; they cannot retaliate or harass you. Again, documentation is very important. Put all of your correspondence in writing and keep a copy for yourself. If you don't get a written response back, fine. It counts against *them*. You are protecting yourself by putting it all in writing.

Share your experiences with others. Don't hesitate to contact the media. But first make sure that you have a valid discrimination complaint. Your EEOC or attorney could let you know. Once a valid discrimination complaint has been determined, go to the media. Remember, I learned after the fact that the hospital I work at was afraid I was going to

go to the media all along. It's a shame I didn't know about that, because I would have acted on it. And last, but not least, I am who I am today because of my audiologist, the Northern Virginia Resource Center, and Gallaudet University. They all encouraged me to stand up and fight for my rights. It's not easy, but with their support and guidance, you can do it. You don't have to do it alone. Remember, changes will never happen unless you take action. Thank you.

Cheryl Heppner: Next we have Jane Schlau. Jane is going to cover two other areas.

Jane: After listening to Brenda, I'm thinking, I need to go home and write letters. I have battle stories, but Brenda shared a very successful story with you. I want to share with you today a story about going to the doctor. We all need to go to the doctor at some point in our lives. I never could have imagined how challenging going to the doctor would be if you couldn't hear.

Since I lost my hearing, I was found to have diabetes. I needed to go to the doctor. My sugar was not in good control, I needed to go to a specialist—an endocrinologist. I was recommended to a wonderful doctor. I think I went the first time with my daughter. Big mistake! The doctor did not provide anything for me and I didn't ask. But then we were getting serious; my medications needed to be changed. I didn't want my family involved. I'm an adult, I could take care of myself. I have a right to know what they are telling me, how to treat myself, and I figured we would find a way.

Well, the doctor was really nice. He wrote and I could lip read him, no problem. But along with diabetes, you need to know how to eat. He had classes and services and a nutritionist to help his patients. So I scheduled an appointment for the nutritionist at the doctor's recommendation. I told them I would need an interpreter, and they said, "We don't do that."

I said, "But I need an interpreter. I can't hear and I need to understand what the nutritionist tells me."

We had a discussion and I had an interpreter the first time. I understood, but, I also speak for myself. They had no understanding why I needed that interpreter. So, the next time they refused to provide it, but they said they will give me extra time so if we need to write, we can write. I thought, I speak English, I write well; I will try.

I arrived at the doctor and there were three girls in the office. The first one was reading a magazine. The other two were doing each other's hair. I went in and sat and waited. I was waiting forever. I had an hour appointment for a half hour visit—double time. The first half hour I sat in the waiting room. They called me in, no interpreter. I could not speechread this woman. We were talking about my health. When I go to the doctor, I'm nervous. Maybe I understood the words, but I did not understand the points. For the next appointment, I asked for the interpreter and they said no. At this point, I'm not feeling well. I call the doctor. I have a TTY with a tape. The doctor gets on the phone, and I explain through the relay that I need to speak with him. I explained that I needed to see the nutritionist, which is a service his office provides to all his patients. I had a

right to go the same as any other patient, and understand every word. He said, "No, we are not paying for an interpreter."

ADA law does not state I must have an interpreter. But it states we must find an amicable way of communicating. So, I ask, if you are refusing the interpreter, how about real extra time for us to write? Not waiting in the room, but real time with the new nutritionist? He said insurance doesn't pay for that. I said I don't care about insurance, I need the service. He said no, we can't do that.

Third suggestion I gave him was to send one of the girls from his office into the room with me and she can type on the computer. "We can't afford that."

I got pissed off. I said, "You can't afford that, but you can afford to have two girls in your reception area doing their hair and reading magazines?"

He said, "I don't like how this conversation is going," and he hung up on me. I have the tape.

I called the relay center and asked for the supervisor. I asked if they could verify for me that this man hung up on me? They checked their communication system and they TTYed me that, yes, he did hang up. I took the tape and wrote a letter.

Now, I'm from New York. I don't have ALDA and I don't have the Northern Virginia Resource Center. I felt very alone, but I had learned that a person can fight battles alone. You need to know what to do, and it was simple. I contacted ADA. They sent me a form to fill out, I included the TTY copies, the dates of all the appointments, what happened, everything. Lots of documentation. You can't have enough information. I sent it away to the ADA and they had it for about one year. I changed doctors in that time. About a year later, I got a letter from the ADA apologizing, explaining that because of September 11th, they had so many cases, they had just been back logged. Would I be willing to go through mediation? I said no. My husband said, "Oh, yes, you will!" So I agreed. I signed the papers. It was a long process. It took a few months after that first letter.

I had been working with Washington, but the ADA set up a mediation center near my home. They set up the attorneys at no cost to me. This really was not about money. It was about a doctor who promised to help people for his career, but could not be bothered with me because I was deaf. Mediation took a full day of my and the doctor's time. Nothing made me happier. He lost a full day. This was not about money, I didn't want money, I wanted him to learn. I wanted to teach the doctor a lesson.

I learned that he had no idea that I really didn't hear anything. He also had no understanding of how tough lip reading is. In this mediation with the lawyer, who kept everything very calm, I had to teach this doctor that, sure, I can lip read your words, but when you finish your sentence, I have no idea what you said. It's pressure, it's my health, it's my life. I can't do that. The end of this process, through mediation, I received in writing from the lawyers, signed by me and the doctor, that any time I go to see him,

he will give extra time. He will write. I have full access to all his services. When I go to his classes, he must provide an interpreter. When I see the nutritionist, he must provide either an interpreter or extra time to write in the nutritionist's office. I was amenable to that.

My lesson? I know this stuff. My background is in special Ed. I know the law. I can fight for anybody. I know who to call, what to do. When it comes to fighting for myself, I usually become jelly, absolute mush. I get nervous. I'm guessing my self-esteem is not wonderful. I'm guessing I feel like I'm a bother because I can't hear. I'm guessing many of you feel the same way. We are wrong. We are each worth that bother—that letter. This was the easiest thing to do. The doctor, when I walked in, he saw me and he was shaking, not me. He was worried I was going to cost him money. He was shocked this was not about money, this was about learning. We each can fight that battle.

Cheryl Heppner: Did you continue seeing the doctor after that?

Jane: He was a really good Doctor, but no. I never called again. My husband said I should have gone at least one time. But you know when you feel drained? I fought the good fight; I won; I wasn't going back. I have a good doctor now. He gives me extra time. He writes every word for me. His secretary knows, when Jane calls, they put me right through because I'm with an interpreter. And I only contacted ADA in Washington. I got the information from their Web site, easy.

Cheryl Heppner: I want to know what it is the people here hope to learn today. May I have a few volunteers?

Audience Member: I came in to find out if churches and synagogues are included in this.

Cheryl Heppner: Private religious organizations are not covered by the Americans with Disabilities Act. However, there are several people within ALDA who are working on trying to promote access for churches and synagogues, and one person who you may know from ALDA news, Nancy Kingsley, just recently received an award for her work this that area.

Audience Member: I wanted to say something about religious services. I'm from northern New Jersey. Services for the deaf and hard of hearing put out a directory and it lists a few houses of worship that do provide interpreters or CART services. One of the things that you might do is contact a resource center, like where Cheryl works, and they may be able to give you a list of religious places of worship where you might be able to get some help.

Cheryl Heppner: What was your reason for attending this workshop?

Scott: I wanted to lend support to you and it's a good opportunity for me to let everybody know here that what Cheryl does as far as advocacy is concerned is amazing. And I never realized how confusing it is to be able to navigate your way

through the government, ALDA, agencies, and everyone involved. I wanted to let everyone know that you really have a lot to learn by joining the ALDA Advocacy group. I have a question, I'm thinking of going back to school. It's a trade school, mostly for older people who want to change careers. They are not going to pay for CART, for my education. I was wondering who would be the best resource to find out whether or not they are liable to pay or whether this is covered under the ADA or not.

Cheryl Heppner: Jane, you probably could answer that because you have had this experience.

Jane: I have lots of school experience. I just graduated with my EdD. I have been in school a long time. When my hearing loss started, I went to school to get a few credits to get my certification in deaf education. In a program for deaf students, I asked for an FM unit. At that time I was hard of hearing. I really can't begin to tell you what I had to go through to get this FM unit. When I finally got it, I asked the professor, who was director of the program, if, when the other students speak, she could pass the mic around? She said to me, if it's important, I will. I was stupid; I said nothing. I came home and complained to my husband. He said I should write a letter.

The next class, I had a hearing professor from Gallaudet. This was a big university in New York. This professor loved overhead and he decided he was going to shut the lights off during the overhead. He asked the class, is this better? They all said yes. I said, "No, I can't see your face." He said, "Oh, that's for you, it's better for everyone else." Now, I wrote a letter.

I was called into the office of the woman who told me she will pass the mic when she thinks it's important. They said to me, "You didn't need to write a letter. It's like you are making a demand."

I said, "I am making a demand. I have the right to see his face, I can't hear him." They changed that, I never went back, they were horrible.

My next experience for my EdD, I started with CART. I personally was not comfortable with CART, because some of the language came out wrong. I change to an interpreter. That school gave me interpreters for every class. Every meeting, social event, and study group, I had two interpreters. I didn't like all their interpreters, so I asked if I could pick my own. They told me to arrange it myself. Any time I had something, I e-mailed the director of special services, told her I had this event. There was no problem. I hired my interpreters for five years. I have learned when you go to school, they need to provide you with accommodations. You need to ask for the person who is in charge of disability services. If they have more than 15 employees, they must provide you with accommodation. If they tell you no, the law is, if similar schools in your area provide whatever service you want, they must follow or prove it's a hardship. I have a friend who was in a similar situation. She asked for CART, but the cost was very prohibitive. They set up remote cart, which was much cheaper. My friend liked it a lot. I would go to your school armed with information. Know what you want, know other options. If they say no, give them another option. Give them the people to call. They can't tell you no; you

would be a paying student like everyone else. You have a right to full access.

Scott: The problem is, this program is becoming a massage therapist. It's a 1200 hour program and \$11,000 for the education. CART for 1200 hours, that's going to come to about \$140,000 or \$150,000 dollars. So, they are telling me it's a hardship. The school is a small school. They don't have the student services or anything like that. I want to know what my rights are with this specific situation. So, I was wondering where I go to find that out.

Cheryl Heppner: If it's a very small operation, and there are only a couple of instructors, then they could say that it's an undue burden to provide those accommodations for you. However, there still must be something else that would be acceptable to you. So, I encourage you to try to figure out what that might be. And by the way The Gallaudet Law Center has disbanded. Some of it has moved to NAD's law and advocacy center. I encourage you to talk to them about options. You can also get in touch with your ADA technical assistance center for your region.

Scott: On the same subject, how much do you have to settle for a reasonable accommodation? Working for the Department of Justice, my employer would have new programs for computer training, I told them in advance about who to contact for CART, but when the time came, nothing had been done. Initially, what evolved was that my particular boss said he would personally help me to learn the program after I had gone and spent the time with people. I couldn't understand enough to go through the program. And I wondered afterwards, did I really have to settle for that?

Cheryl Heppner: Talking about the Department of Justice as your employer? I don't believe I want to go there. That's a whole separate ball game because you are talking about a Federal program, which is a different set of laws, not the ADA. You know, when we talk about undue burden under the ADA, or even a reasonable accommodation, the question of cost comes up often. I'm going to use the example of a doctor's office. Often you want an interpreter, CART, or something like that, for medical setting, and they will say no. They will say the cost for you to come to my office is \$60.00 a visit or something like that and the interpreter is going to cost more than that. But that's not the issue.

When they are looking at the burden, they are not looking at the cost of one office visit and the accommodation needed for that visit, they are looking at the overall financial picture of that office and how much cash a doctor takes in. So, if you think about it, you may go into a doctor's office, and the doctor will have all this equipment that you may not need. He includes his overhead for that equipment in his office fee for all his patients. Accommodations should be part of his overhead and need to be included in his fee, too. He has to budget and plan for it.

Audience Member: This is in reference to Scott's situation. The massage therapy school is very small. One possibility for him to investigate is if vocational rehabilitation services will help pay part of the cost of CART services. One advantage of CART services is that when the CART worker has finished, they can have a printed transcript of the session. This transcript could be used in many ways. Other students could use it

as notes. Maybe if there are other hearing impaired students that need CART services, that would help split the cost, so that it doesn't take such a large chunk of their overhead costs.

Cheryl Heppner: I did want to ask some of the others what they wanted to get out of this session.

Linda: I guess I didn't know what to expect. I was thinking more about advocacy as a group. Trying to get a law changed or something like this.

Lois Mann: I came to get support and to share my experience. I'm a retired librarian and, while I was working, I had two falls at work. I went to their doctor for Worker's Comp. After a long time, I didn't see any improvement. I was complaining a lot about that, and my husband checked around and said I should go to my own doctor. I told that information to my employer and they didn't do anything about it, so I contacted an attorney. Some paperwork was sent to me, and then I could choose and pick my own doctor. So, I have had a lot of success in choosing my own doctor. I wanted to share that information with you and let you know that you do have choices. But it's our responsibility to look for what those choices are and get in touch with those resources.

Cheryl Heppner: How about anyone else? What did you hope to get from this?

Audience Member: I'm here for work related concerns and issues. I currently work with a company that employs a little over a hundred. My concern is the training videos that don't have closed captioning. My choice is to take it home and try to listen to it there. I would like to advocate for closed captioning videos and some type of interpretation during training. I do have some hearing, but I do not sign. So, I don't know what kind of interpreting could happen to me for training. My question really is about the videos: How do I go about having that changed? Do I go directly to human resources and make a request?

Cheryl Heppner: I couldn't give you an answer to that in this short period of time. The things that you all have said here today are issues that are all being addressed at the national level.

Now it's time for me to talk about what may be happening in your communities, schools, and work places. It's really tough that often we are the only ones in that doctor's office or that school or workplace, and it's tough to fight for these things alone. We are trying to set up some support systems. All of us can do that.

The second thing is that, in my own work, I have found that there are some things that can be resolved at a local level. However, others have to have a national law passed and then someone has to actually enforce the law.

I have been ALDA's face in Washington, D.C. for many years, and I can tell you that there are many things that are much more complicated than they may seem.

Audience Member: I know, when I was living in the Washington area, it was great to be able to use the available resources, but where I live now, Florida, I have lost that. Is there is a clearinghouse where we can get this information?

Cheryl Heppner: Would anyone else like to see a clearinghouse for that type of information?

Audience Member: I'm in the process of trying to get CART in my synagogue. I don't want it just for me, I want it for anybody, in any of the synagogues. Right now, I'm writing letters to the editor of the New York Times. They are not aware that Christian churches invite me to the Christian ministry for the deaf all the time, but the Jewish ones don't. I think it's time they did. I'm trying to be an advocate for them. I had a problem with my synagogue, and I went to the rabbis and they gave me copies of the sermons that they are going to be giving for the holy days. We have had speakers come to temple, and I felt like I have paid my membership dues and I deserve to hear the speakers, too. But they would not cooperate. Now I know the ADA doesn't apply to synagogues, but I threatened them. They had no idea. They set up a tape recorder for me and had it transcribed. That helped. But the CART idea would be a big help.

Cheryl Heppner: In hearing your stories about places of worship, you go to those places for spiritual support, and I think that we have to work together to find a way to explain the experience of being late deafened. You can't make everyone deaf, of course. But as we were learning to become deaf ourselves, we have had to learn how to develop the vocabulary and words that will help other people "get it". Having a tape recorder and having it transcribed is nice, but it doesn't give you the experience of being included in the audience.

Cheryl Heppner is the executive director of the Northern Virginia Resource Center for Deaf and Hard of Hearing Persons, the chair of the movie captioning committee, and the vice chair for the consumer advocacy network.

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