Back to the Future
Back to Chicago
ALDacon '98
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Selected Proceedings from ALDAcon '98

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The ways and means of dealing with a disability are unique to each individual; one size definitely does NOT fit all. It is this fact that makes it so important for those of us with hearing loss to share coping strategies and life stories as we do at the annual ALDAcon.

Unfortunately, many people are unable to attend the "con," where the material in this book was presented in workshops. Luckily however, all of us can have a front row seat by reading the ALDA Proceedings each year.

In this year's Proceedings you will find articles on cued speech, technological advances, and legal issues in regard to the ADA &ndash; to name just a few topics. Most important, the information herein can, I hope, provide us with the means of plotting our own individual course in life despite the presence of hearing loss.

As always, ALDA is in debt to the University of Arkansas for their participation in the publication of this year's Proceedings.

Carolyn Piper
The University of Arkansas Rehabilitation Research and Training Center for Persons who are Deaf or Hard of Hearing (RT-31) is pleased to have assisted ALDA in preparing and publishing this book, _Back to the Future: Back to Chicago_. This book focuses on material presented at ALDAcon '98, the annual conference of the Association of Late-Deafened Adults. The material included was presented and prepared for publication by consumers, service providers and advocates who are committed to defining and meeting the needs of late-deafened adults.

The conference convened September 2-6, 1998 in Chicago, Illinois. This Tenth Annual “Meeting of the ALDAcon Clan” gave participants the opportunity to meet new family members, reminisce with the old, and gather the news that has occurred between the times. Special thanks go to Mary Clark, president; the program co-chairs, Steve Larew and Kathie Hering; and the conference planning committee under the leadership of Karen Krull. As evident by the number and enthusiasm of persons in attendance, it was clear that the conference provided a viable national forum for consumers and advocates who are interested in late-deafened adults.

Credit for this document belongs to the many individuals, organizations and programs that made the conference possible. We would like to especially thank all of the CART operators and the presenters for the time and effort they devoted to the preparation of their manuscripts and willingness to work with us during the editing and publication process. We have tried to faithfully maintain the content and ideas of the individual authors. We readily accept responsibility for any deficiencies in the editing of the material and hope that our work has only served to clarify the ideas expressed by the authors.

We also want to sincerely thank the leadership and members of the ALDA board, both past and present, for their support for the completion of this manuscript. In dedicating this publication to late-deafened adults, it is our hope that this document will serve as a printed record of the proceedings of this conference and become a resource to the field and those persons who were unable to attend the conference.

I would also like to thank RT-31 faculty and staff – Carolyn Kobek, Cheryl Wilcox, Paul Geyer, Kim Knerem, Heidi Lefebure, Mary O’Rourke, John Schroedel, and Kathy Wheeler-Scruggs – who provided assistance in preparing this document for publication and dissemination.

Douglas Watson, Ph.D.
Little Rock, Arkansas
May, 1999
RESOLVING AN IDENTITY CRISIS AS A LATE-DEAFENED PERSON
A KEYNOTE ADDRESS

I. King Jordan

"Back to the Future" is the title of this "con." Also, "Back to Chicago." ALDA is celebrating ten years of existence. I know a little bit about ALDA's history. I am aware of the fact that it pretty much started in Bill Graham's kitchen. I also know the first few ALDAcons were small. There was some struggling to assure that the group would stay and succeed. But, wow, you've made it! This room filled with people is real evidence that ALDA is strong. Look around the room. Look at the number of first-time people who are here. Congratulations.

I want to tell you a story. Now, in retrospect, it's funny. But at the time, I was nervous. I went to Italy for a two-week vacation in August. The vacation was a walking tour of Tuscany. One of the things I took with me was a belt with two water bottles. So I had two water bottles and a pouch, like a fanny pack, but bigger. In the pouch I had my passport, my camera, my binoculars, some money and other things.

We took a train to one place and a train to another place and then we got off and got a bus. While I was on the bus, I undid my belt. When we got to the small town where we were going, we became so excited that we carried off our suitcases. I forgot my belt. Left it on the bus. Forgot it with my passport, my camera, my binoculars.

We tried to call the bus, but the woman at the hotel didn't speak English. We didn't speak Italian.

So, I changed my shoes, put on my running shoes, and I ran to the bus station. The bus was gone. But, I decided I would explain to these Italian men what happened. Now, remember, they obviously don't speak English. I don't speak Italian.

So, I just didn't talk. Because I know if you talk, then people talk back to you. Instead, I explained in big gestures. They understood me in one minute. They then picked up a radio and called the bus that was on its way to the next town. The driver came back with my belt. Gave it to me. The rest of my vacation was fine.

I could never have done that shortly after I became deaf. Never. I wouldn't even have run back to the bus. I would have given up. But now I do it. I will find a way, even though I can't hear. That sounds so simple, but it's really a hard lesson. If you don't grow up deaf, it's a much harder lesson. It takes a long time to learn it.

I talked at the 1991 ALDAcon about my experience becoming deaf. A simple explanation: I became deaf as a result of a motorcycle accident when I was 21. I was in the U.S. Navy at that time. I became deaf very suddenly in a culture that knew nothing about deafness. It's amazing that military physicians knew nothing. Probably because people can't go into the Navy if they are deaf or hard of hearing; therefore, they never have to deal with hearing loss. So, they began my treatment by telling me, "You have suffered a very serious head trauma. You have lost your hearing temporarily. Don't be concerned. It will come back."
That had to be the worst possible thing that a physician could have told me. But, they told me that again and again and again during that year. I had no ALDA, no support group. I promise you, nothing is more important than a support group — being with other people who have experienced the same things, and who can share experiences with you and help you see that life goes on.

I wish ALDA had been there in 1966. I never used the word "deaf." Never. I never said I was deaf. I didn't think I was deaf. I was a hearing person who couldn't hear. Now that sounds ridiculous to say. But honestly, that's what I felt I was.

I stayed in the hospital for more than a year. It was a slow recovery, but it wasn't a year's recovery. I stayed in the hospital for a year because the Navy didn't know what to do with me. The U.S. Navy, they couldn't have a deaf person. But other than the deafness, I was fine. So what do they do with me? For a time, I actually had a job. I worked at Blue Cross/Blue Shield in downtown Washington, D.C., and lived in the hospital room in Bethesda, Maryland. So every day I took the bus to work and then took the bus back. I ate breakfast in the hospital. I ate dinner in the hospital.

Finally, someone told me about Gallaudet University — Gallaudet College at that time. So I went to visit. Now, if you were thinking that's it, a solution, right there, deaf man, finds out about Gallaudet College, enrolls and everything is fine. No. I arrived at Gallaudet College, had no signing skills, had never met a deaf person. I walked into the student center ... and was shocked. Really. I didn't know how to deal with it.

I left scared. I thought, "I can't go to college there. I can't understand speech at the University of Maryland. But I can't understand sign at Gallaudet College, either. So what am I going to do?"

Finally, a friend convinced me, "Go. You will love it there — you will do well there."

So, I went to Gallaudet, and basically it changed my life. I did learn signs fairly fast once I got there. But, honestly, for all the years I was at Gallaudet, I wasn't a deaf person. I was a hearing person who couldn't hear, getting an education, knowing that next year or two years or something my hearing would come back and I could thank Gallaudet College for providing me with an education, but that would be that.

I really learned a lot and had a wonderful experience at Gallaudet. But I could have had a much better experience if I had gone as a deaf person. But I didn't, I was still struggling to adjust to deafness.

Then I went to graduate school and that was an amazing situation. In the 1960s, there were no support services at colleges or universities — no interpreters, no note takers, no sympathy for students who were deaf. You're a student. You do what you need to do to get the information. I remember one class I had with a guy named Steve Brown. We had a seminar in a lounge room, because all the classrooms were used. Every day Steve would lay down on a couch. When he wanted to say something, his voice would just float up from this couch; and you can't lip read somebody who is behind the couch. It was an awful experience.

But, I was still focusing on deafness and what was wrong. I needed to accept deafness and move on. I finally realized and understood that I had to do that. If you do it yourself first, it will make life easier for other people to do it.

Deafness is inconvenient. Deafness can sometimes be a pain in the neck, and when you want to communicate with somebody who doesn't know about deafness, doesn't know sign language, and sometimes isn't willing to take a minute and write, then it can be a pain in the neck. But hey, life's
tough. So we need to learn, find a way to deal with deafness, even though it's an inconvenience. It's important for me to accept that. It's important for others to accept that. It's important for you to accept that.

I remember once I went to a black tie event in New York City. A very well-known physician came up to me. This was after I became president of Gallaudet University, so many of the people at this dinner knew who I was, and this physician also knew. He came up to me and he started to talk. So I looked at my interpreter. He started to talk again, so I looked at my interpreter. He tapped me. He looked at me. He said "Why are you looking at her?" I said, "She is my interpreter. I look at my interpreter." "But how can you expect to understand me if you look at your interpreter?" It was, of course, the old, "If you just try harder, you will understand." He basically said that to me. He said, "No wonder you can't understand. If you're going to depend on an interpreter, then of course you'll never understand me."

So other than wanting to throttle the guy, I very patiently explained. "No. You don't understand. I'm deaf. For me to understand, the easiest, best, most complete way is to watch the interpreter. Now, if you have something to say, go ahead."

But that happens. It happens with children. It happens with adults. We need to educate people that it's not right, that trying doesn't make you a good lip reader, that trying doesn't make you hear again. For me, the easiest was sign. I always use interpreters in meetings, because I know I get everything that is said. I have a good interpreter, I'll receive everything that hearing people do, and sometimes even a little bit more than hearing people do.

I'll tell you one interpreting story. Bob Davila, my good friend from the National Technical Institute for the Deaf, and I go to Congress every year and sit and testify before a congressional committee. One year I went to testify, and my interpreter, a very, very skilled interpreter, had gotten permission to walk around behind the individual Congressmen as they spoke to help me understand who was asking me questions.

So she was walking around interpreting. Then there was one point where there was a little pause in the proceedings. The Congressmen's chief of staff whispered to him. My interpreter could hear the whispering, so she signed what the staff person whispered. So sat there and saw what was coming next before it came. Then I thought a minute and had my answer all ready.

So sometimes interpreting not only gives us equal access, but better access. If we have less access so often, then it's fair once in awhile to get more access.

My message is short. My message is that I now know I'm a deaf man. I now know I'll never hear again. I now know, that for me, the best communication is visual communication and sign language, and because I know it inside me, it's easier for me to convince other people of that fact.

If you don't know yet, that's all right. It took me probably five or six years from the time I became deaf until the time I said, "Okay, I'm deaf and will be deaf for the rest of my life."

But if you want advice from me, my advice is simply this: the faster you can do that, the faster you can say, "Okay, maybe I don't want to be deaf, maybe if I could choose I would be hearing, but it doesn't matter. I can't choose. I am deaf," then the faster you will be able to get on with the rest of your life and be able to make the kinds of decisions and adjustments that you need to make.
Perspective, how we look at things, how we identify ourselves, is very important. I know that, because you came here, many of you already have done that. But many of you are leaning in that direction. Talk with people who came to ALDAcon 2, 3, 4, 5, 6, 7, 8 – talk to them, share their experiences, so that you too can formulate your identity.

Thank you very much.
Before I get into the main part of my speech, let me tell you a little bit about myself. I have to say that I've had a fairly interesting life. I grew up in a Spanish-speaking family, all of whom were hearing. I lost my hearing after I acquired language. But the language I had acquired was Spanish rather than English.

I come from a large family. My parents came to this country from Mexico. All of us in my family were hearing and in good health. My father died when he was 38 years old and left my mother with eight children. Two years later I became deaf. But in a family where the search for food, shelter, clothing, and work was a constant struggle, not being able to hear was no big deal. So life for me didn't really change.

Through some contacts that my mother made, I was sent to the California School for the Deaf, where I began my formal education in English. When I was a boy growing up, I used to think in Spanish and sign in English. By the time I was about 13 or 14, my English had improved to the point where I started to think much more exclusively in English. Now I am an English thinker, even though I can speak Spanish when I have to.

One thing that makes me different as a late-deafened person is that all my education was in residential school environments. I went to a school for the deaf when I was eight, and I stayed until I graduated from high school. After that, I went to Gallaudet College. From there, I went on to other things. But until I had graduated from college, I had not had much experience with hearing people. My first real experience with hearing people was when I was in graduate school, at the City University of New York (CUNY).

Then I went to Syracuse University, where I was fully integrated without adequate support services. Those were the old days. Remember them? The old days were when people who were deaf had to learn to swim or sink. For that reason, very few people were able to acquire advanced university degrees. When I got my Ph.D. in 1972, I was the fourth Gallaudet graduate in history to actually earn a doctorate. I'm very proud of that. I wanted to be first, but no, I was fourth. Now there are hundreds of deaf people with Ph.D.s, which is a reflection of the progress that we have made.

I have really been very fortunate in many ways. I thank God for all the blessings that He has given me. Because of my education and the support I have been given, I have been able to open doors both for myself and for other people as well. But there are other people who will follow us in the future.

This morning, I want to talk to you about technology and the impact that it has had not just on society in general, but also on the quality of life for people who are deaf. I straddle two generations. I am old enough to remember the days where there was almost no access into the hearing community for people who are deaf. The deaf community and deaf individuals were truly isolated
from people who could hear. Now, some 50 years later, I can tell you that the situation is much, much better.

So I want to start my presentation and how it relates to technology with a little story. I suspect that there are some of you here who remember back to 1964, when the World's Fair was held in New York City. For the first time ever, there was a demonstration of what they called “the picture phone.” I was one of the four deaf people invited to New York to participate in that demonstration.

I can't tell you the feelings and the experiences of that day. I was so excited and nervous. The four of us sat in front of a television camera with a small monitor. When it was turned on, I could see people who were my friends in Los Angeles and in Chicago. We started to communicate by sign with each other. I almost cried. I was thrilled. The demonstration lasted about half an hour. We begged them to extend the demonstration for half an hour longer, and they did.

That night I went home on cloud nine and was filled with dreams. I couldn't sleep that night. I could sense that the future had arrived. I could see that deaf people would be able to turn on their video phones and be able to sign and talk with each other. As for those people who couldn't sign, they could write and display their writing to the camera. Some people would even be able to lipread each other over the video telephone.

It didn't happen, though, and the reason was simple economics. You don't have to see other people to communicate with them. Further, in a free enterprise environment, such as we have in this country, the bottom line is money. Improvement has come because there are people who are deaf and hard of hearing who have now become an economic force in their own right. This is important for us to understand.

During my early years, there was something extraordinary about the first-born child in a family with deaf parents. When that child reached the age of three, it was considered magical because that's when deaf people installed a telephone in their home and started to teach the three-year-old to hear and interpret. You may think, “Oh my goodness, that's too much responsibility for a child.” I look back on it and figure it was probably true. It did appear to be an enormous burden and heavy responsibility to place on a child. But there was no other way for deaf people to communicate with the hearing world via telephone except through their children. Yes, you could probably concede that in today's standards and values, a certain amount of abuse occurred, but not intentionally. The need of deaf adults to communicate was the force behind that abuse.

There were other ways that deaf people used to communicate when, for example, a child was sick. Deaf parents would get up in the middle of the night, walk over to the next-door neighbor, knock on the door, and embarrassedly explain to their neighbors that they were sorry for disturbing them in the middle of the night, but they needed help to call the doctor or an ambulance.

I personally never used a telephone when I could hear. My family was too poor. So I didn't use a telephone until I was almost 30, when TTYs first came out. You remember the early TTYs, the Western Union teletypewriters, the big ones, those monster machines? Remember those? They clattered; they were noisy. They were awful. But they allowed us to communicate. I was thrilled.

Now I want to tell you a little bit about Rochester Institute of Technology (RIT). That's our host institution, of which National Technical Institute for the Deaf (NTID) is one of seven colleges. It is one of the “most wired” universities in the country. At NTID we utilize and benefit from all of the technology that is available. We were established to provide options for deaf people.
NTID was established as the result of a national study that was made in 1965. The report found that our nation's schools were not doing a good enough job of educating deaf persons. For example, it was found that, on average, a typical 18-year-old deaf student read below a fourth-grade level, that 80% of all deaf adults were working with their hands, mostly in manufacturing jobs; and that many educators who were teaching deaf children were not qualified for their jobs. In addition, there was insufficient emphasis on content teaching at the secondary level.

In other words, there were very few young deaf people who were being properly prepared for college. At that time, the only college for the deaf in the world was Gallaudet College. Gallaudet was a very small school at the time. It enrolled 250 or fewer students. That was the only option for many young deaf persons like myself. I remember as a high school student, would worry about my future. Gallaudet could only admit 40 or 50 students each year. I worked hard to make sure I was one of those 50 students. There was a very critical need for more postsecondary opportunities. As a result of the 1965 study, massive federal support and grants were made to train more teachers of the deaf and create more college-level opportunities for deaf persons. NTID was established as another option to prepare deaf people for careers in technical fields.

NTID celebrated its 30th anniversary in 1998. The Institute opened its doors in 1968. Thirty years later, we have a proud record of success. My university, RIT, was selected to host NTID because of its emphasis on technology as well as its cooperative education, which requires that students must have work experience before they graduate. RIT has been one of America's pioneers in cooperative education. We have found over the past 30 years that cooperative education often opens doors to permanent employment. In addition, students' grades improve and this has a multi-layered effect on the community, in the technical fields, with employers, and with employees.

One example of technology that has helped us in recent months is the WyndTell pager. I do not work for this company and I'm not promoting its products. But the point I want to make is that WyndTell pagers are an example of the kind of current and recent technology that really improves access for deaf people. I love my WyndTell device. It's like my American Express card – I don't leave home without it. This device allows me to send faxes. I can get e-mail. Recently, this company tested a live relay operator system with a turn-around time of about five minutes or less. I don't even travel with TTYs anymore. The WyndTell is a wonderful device. It's not the only system available, of course. I mean, we have got the attention of the whole pager industry. And the pager industry now is considering design features as additions to their systems so that they can expand access for people who are deaf or hard of hearing. It's wonderful.

I think that the ultimate development will be a cellular TTY, a small device with a keyboard that you can use to have real-time communication. We are not there yet. I want to be able to communicate in real-time with people rather than the current technology, which requires that we send a message and wait for a response.

Now, the Internet – there are so many things that we can do with it. The Internet expands our horizons. There is nothing that is out of reach there. But we need to understand it. We need it in all schools and colleges. To use it effectively, we need to continue to emphasize development of computer literacy. It is a priority at NTID. Every student who leaves NTID must be computer literate. They must be able to access anything they can on the Internet, not just play video games. They must be able to do operations using the Internet. They must be able to have access to educationally-related activities. They must be able to do assignments with computer support.

Two other things are also important. The two most common daily access necessities for the deaf are obviously TTYs and, secondly, interpreters. It was not always that easy to obtain that kind of
support. For many years, deaf people would go to professional meetings or large conventions and hope they would find someone willing to volunteer to interpret.

We have now created the profession of interpreting. Interpreters are professionals—persons who are trained, qualified, and certified to provide a service. But even so, although we have made great progress and now have many professionally paid interpreters, we don't have enough. We are often misled by looking at places like Chicago or large urban communities like New York or Los Angeles where we see a good level of support, and determine that things are fine. But they're not. There are many small communities around the country that lack a sufficient number of interpreters.

The Americans with Disabilities Act (ADA) has made interstate relay service a requirement and a right. This has been wonderful. Before, relay services were limited to in-state services only. While this was good, I couldn't, for example, call from Connecticut to Massachusetts. Now as a result of the ADA, I can talk to any hearing person in the nation. Because of this service, we also have improved employment opportunities. Deaf entrepreneurs have more access because they are independent, communicate over state lines, and can involve themselves in interstate commerce. So accessibility, while it is of great social need, spills over into many other important areas, such as commerce, business, and employment.

Let's talk about hospital interpreters. Deaf people really require some kind of support when accessing medical services, especially when they sit down with a doctor and discover that they don't understand what is being explained about their condition. The medical staff often shares information with family members rather than with the deaf person. When that happens, the deaf person has no idea what's wrong with him or her. It's an incredible disrespect to the person. It's a terrible mistake which stresses the need for interpreters.

Currently, different communities enjoy different levels of interpreter support in the medical field. I'm proud to tell you that in Rochester, the largest hospital in the city has three full-time interpreters on staff, plus they also have access to freelance interpreters as dictated by necessity. They do this because Rochester has a large population of deaf people. It has a large deaf community which is very well educated and not passive about voicing needs and demanding responses. But there are many places in this country, especially in rural areas and small towns, that do not have the population-backed political clout to really force the system to respond to the needs of its deaf citizens.

So organizations like ALDA, as well as other organizations, can truly help because ALDA can reach out to others in the late-deafened community and deaf people can help each other. We should either stand together or fall together.

Television captioning was started by the federal government in response to demand by the deaf community. Films, especially entertainment films, needed to become accessible. Many people consider captioning one of the most critical developments of recent times. Perhaps the two major access developments of our era are access to the telephone and access to television through closed-captioning. These two developments stand high on the all-time list of achievements. Deaf people and their hearing friends are responsible for advocating for both achievements.

The person who is considered to be the "Father of Captioning" was a deaf man, Emerson Romero. He did freelance captioning of movies. It was an independent effort he couldn't sustain because of the cost. But it was picked up by others and later became an important federally-supported program. It's something to remember that we often have to wait for deaf people themselves to solve problems.
Even so, as the poem says, "We have many miles to go before we sleep." As I mentioned a while ago, the ultimate goal of communication access is that we have instantaneous communication over the telephone lines. When your car breaks down and you are driving in the country, you more likely than not have to stand there and hope someone will see you and offer you help. Or maybe a state trooper will find you. This is where access to a telephone, perhaps a cell phone, would be a blessing. It's important. We are close, but we are not there yet. We are not yet completely independent, functioning people.

We need more interpreters and access in hotels. I travel frequently. My office often calls ahead and makes reservations and requests technology to provide access for me. I need the signaling devices, such as a doorbell device, a TTY, and flashing lights to signal a ringing telephone. These are things that are a daily requirement for me. But there are still many hotels that don't know what they need to do, and don't provide assistance. They are not opposed to deaf people, they are ignorant. It's a big country. We have a lot of public education to provide. Most businesses don't understand their responsibilities. We have to tell them. You don't have to fight every time that something is missing, but you can make it clear that it's required by the law. Therefore, the extent to which the law will be fully implemented is up to us.

I know that all of us who are deaf have developed what I call "tricks of the trade" – survival skills. At the airport, if I have a ticket to Rochester, what do I do with it? I walk around. I look at other people's tickets, their boarding passes. Sometimes they catch me looking and they try to figure out what I'm doing. I only want to know where they are going. If I find somebody going to my city, I follow that person. That's how I survive in airports, because there is no way for me to know if, for example, the gate has been changed, if the plane is going to be delayed, or whatever else may have happened. So we all develop our own skills in surviving. That's what I do. If we push – and we will – then maybe we will get visual displays at airports. The information that you don't hear should be put on visual displays.

I'm jumping ahead a bit in my presentation, but I want to give you some information about NTID and expand a bit on how and why it was established. It's not the purpose of my presentation to promote NTID – but it's a special program. NTID is about specialized programming for people who are interested in technology, science, and mathematics. As I mentioned, prior to 1965, 80% of deaf people were employed in manufacturing positions, mostly in assembly plants.

The only professional employment opportunity for many college-trained deaf persons was to teach in a school for the deaf. I became a high school mathematics teacher. I don't regret it. I had a wonderful career as a teacher and I enjoyed that career. But I became a teacher largely because I had restricted opportunities.

NTID was established for the purpose of expanding those opportunities. We have 1,200 students; 40% of them study in regular programs at RIT. They study in the six other RIT colleges; among the most popular colleges attended by deaf students are the colleges of business and engineering. We provide quality support to students, and I'd like to share some information about that with you.

In 1997, a typical year, we provided 14,000 hours of notetaking assistance to over 400 students attending regular classes at RIT. Those notetakers are recruited from the brightest hearing students in the RIT student body. They are trained to write good notes and to organize their notes in a way that will be helpful to deaf students who can't look at interpreters and take down notes at the same time.
We provided 82,000 hours of interpreter support in mainstreamed classrooms at RIT last year. In addition, we provided interpreter services to help students access extra-curricular activities. For example, we have three deaf students on the varsity wrestling team, one of them an NCAA champion, so we assigned a full-time interpreter to the wrestling team. The team practices hours and hours. They go on out-of-town trips. So with the interpreter, the deaf students get full benefit of the varsity athletic experience.

Interpreters are not cheap. Interpreting is an expensive service. But this is not charity. This is a very valuable and wise investment of our public money to educate deaf people. Data shows that it pays back. We have cooperative research going on with the Internal Revenue Service (IRS) and the Social Security Administration. The studies project tax payments over 35 years of work life. We know, for example, that 29% of all deaf people who are at least 30 years of age are still on SSI or SSDI. We also know that the more education a person has, the less likely he or she will continue using public entitlements. Our studies indicate that a deaf graduate of RIT with a bachelor's degree is very much less likely to continue to depend on entitlements. In fact, only 6% of them are still on entitlements by the age of 30.

As I've said before, technology has made a great impact, but it is not technology alone. It is the fact that we have access to education and good training and the preparation for the world of work. That's what empowers us. This is what makes us a strong community of individuals with the ability to advocate for ourselves. It's not that we don't need hearing people; yes, we need hearing people. They are part of the larger community of people. We relate to them. We work closely with hearing people. We have many friends who are hearing people. Our family members are generally hearing. But we are also helping ourselves as a result of the opportunities for advanced education. No one knows that better than I do, because I'm the only person in my family who graduated from college. Ironically, that opportunity would not have been possible if I hadn't lost my hearing. So I count my blessings.

I do want to tell you about a new program at NTID: the Northeast Technical Assistance Center (NETAC). This is one of four regional centers funded by the U.S. Department of Education. We competed with many colleges in the east for a $5 million grant to manage this center. NTID is the perfect institution to have that responsibility because, over the last 30 years, we have learned more than anybody in the world about how to support a deaf individual in a fully mainstreamed, integrated environment.

As we developed our support services and all of our processes and systems over the years, we trained individuals to reach out to other colleges serving deaf students to share our knowledge and expertise. Through NETAC, we can reach and assist many more students by working with the community colleges in the northeast area. NTID is only one of many colleges that serve deaf students. We are the largest technological college serving deaf students. Our undergraduate enrollment is about the same size as Gallaudet's. We want to increase the opportunities and allow deaf students to access whatever learning environment they want and need.

But I want to say something else. All of this application of technology also imposes large, important responsibilities on teachers. Teachers need knowledge of computers and technology, and schools need resources. Often, schools lack resources, time, and energy to really provide the professional development that teachers need to become more effective. Four years ago, when I was working for the government, I spoke at the National Education Association conference in San Francisco. One speaker at the conference said that only 9% of America's teachers were getting on-going professional development support. I was startled by this fact. That means 91% of teachers don't
get many opportunities to crack a book often enough to improve their teaching abilities and knowledge. It’s a big problem.

I think some of you have gone to the movies that are promoting captioned films. You can go to a regular theater and see a captioned film at special times set up for deaf people. I saw “Titanic” captioned and in a regular theater. It was wonderful. But we need a system that will allow us to watch captioned movies at regular showing times. I know that at WGBH, the Caption Center is developing a system to caption films that uses a device like a rear-view mirror. It still needs to be refined. Obviously, you can’t hold a mirror while you are watching a two-hour film. But technology is getting there. It’s coming.

I want to close now by talking about research. As good as our progress has been, as great as the measure of our satisfaction has grown, we still know next to nothing about how technology actually impacts deaf learners in terms of learning, understanding, and acquisition. It is important for us to be analytical and self-critical because it’s the only way we are going to find the answers. For example, I said earlier that in 1965 a national study indicated that, on the average, an 18-year-old deaf student read at a fourth-grade level.

Now, 30 years later, there has been no significant improvement in the reading abilities of prelingually deaf individuals, even though we have made progress in measured cognitive acquisition of knowledge and information. There has been no real growth in language and communication ability – which leads me to mention that the Chronicle of Higher Education published an article last June by Ed Neil, the director for faculty development at the Center for Teaching and Learning at the University of North Carolina at Chapel Hill, in which he wrote, “We need research. We need to research the benefits of technology in the same way that we research any other educational process.”

We are learning. But we need to know how best to use new technology to help young people to improve their language ability, their ability to access information, and how they can use that information in a practical way. We don’t know, for example, how deaf children view captions. We don’t know how deaf children “look” at interpreters. We don’t want to be too quick to assume that putting an interpreter in front of a deaf person will close the communication gap.

Captioned films for those of us who are highly literate are wonderful. But how does a person who has language problems view captions? I think we need a very strong research program. NTID is going to work in this area, and I hope we can direct our resources in such a way that we can set up a niche for that research so that we can get the answers we need.

Deaf people comprise a powerful political group. They played a significant role, for example, in getting federal legislation passed in recent years – such as the Decoder Circuitry Act. So you have to really appreciate the power of our community. We are not that many in number, but the strength of our community and the strength of our common voice is made stronger when we choose to work together on common goals.
ADA CASES AND SETTLEMENTS,
DEAF AND HARD OF HEARING PEOPLE

Alan R. Post

Author's Note: Remember, this is general information, not specific legal advice. You will need to see your own attorney for specific legal advice.

I've been a lawyer since 1972. I have done mostly corporate work. I have had to go to hearings every now and then. It got to the point in 1987 where I refused to go to any court hearings unless there was a skilled "realtime" CART (computer-assisted realtime translation) court reporter taking down every word. I was finding that I was spending all my time figuring out what was going on - with no time left to think and operate like a lawyer. The only way to overcome that was with CART. I had tried an FM system. FM systems are great if you are listening to only one person, but they don't pick up all the sources of sound in the court room - the judge, the witness, and the other attorneys.

Now, before the Americans with Disabilities Act (ADA) was passed, my employer would not provide realtime or an oral interpreter. After the ADA, the utility company I once worked for had the same reaction. Before I was hired, I told them what needed. I thought they understood. But apparently they did not, for they did nothing to help me.

The ADA, somewhat unrealistically, assumes that we can bargain on an equal basis with our employers. The only legal remedy is to complain to the Equal Employment Opportunities Commission (EEOC) or state human rights agency where you are. You are supposed to do that within 6 months. But my practical experience teaches me that you should file a complaint as soon as you are sure of the situation. That means within a month or two. You should be prepared to ask for the right to sue in a letter in about 3 months. Then you have only 90 days to file a lawsuit. You should have an attorney file the complaint on your behalf because many employers don't get serious in talking about accommodations for their employees with hearing loss, until after a lawsuit is filed.

Once you have the attention of your employer, you need to have somebody negotiate for you to get the accommodations you need. I have been through that process twice. It is not easy. You get a certain name that follows you around for being lawsuit-prone. But you must make a choice of either trying to be a good, effective employee with help, or being ineffective because you cannot hear well enough to do the job well.

I have a 22-year old daughter who uses a wheelchair. People can see what her disability is. Most people understand curb ramps for people in wheelchairs. Hearing loss, because it tends to be invisible and is less understood, can be more difficult to "sell." So we must work harder to get what we need.

One of the first issues under the Americans with Disabilities Act is whether or not one is "substantially" impaired enough to be considered "disabled" under the ADA law. In other words, does the hearing loss have a "substantial" impact on your major daily living activities?
Fortunately for us, most of the cases tried thus far acknowledge that a severe to profound loss is a covered "disability" under the Americans with Disabilities Act.

The EEOC guidelines are also clear that the presence of assistive devices, such as hearing aids or cochlear implants, does not matter. The loss is supposed to be looked at apart from whatever you might do to offset its effects. Unfortunately, some judges don't follow the EEOC guidelines as the wording of the statute includes the word "substantial" and, if the judge wants to exercise discretion in interpreting this narrowly, he or she can.

So, it is important to document the hearing loss and to be prepared to explain what it means. It is not, for example, just that you can't hear your spouse occasionally. It has to have an impact on your ability to think and to work. You don't want to minimize the effects of the very real communications barriers.

By documenting, I mean audiological reports and medical exams. The further back you go into your history, the better. If you have an audiological exam just before a lawsuit, that's not enough. You must be prepared to talk about what the audiogram means in practical, everyday terms. Plus, one or more professionals who deal with deafness need to document the functional meaning of the loss and validate your testimony. In other words, you have to reach the judge not only with your own testimony, but with the testimony of experts, preferably two or three, with degrees and credentials.

The ADA also stipulates "effective" communication. Employers and others are supposed to give primary weight to your communication choice, even though the final decision is theirs, subject to court review. If your choice is American Sign Language (ASL), you tell them that; but be prepared to prove that this is the best choice for you, using people with credentials who know you well. Pick, for example, the head of an interpreting agency, or a professor at a local university. Make sure they evaluate your individual situation, and include in their testimony, for example, that you are culturally deaf and that ASL is your native language.

The use of pencil and paper and reading notes back and forth is fine for simple transactions, such as asking for an appointment at the doctor's office. However, if something complex comes up, then an effective interpreter is required. Under the EEOC and Department of Justice regulations, you have the right to stipulate what your choice for communication is, and they are supposed to honor that choice.

It is also important to remember that in employment situations under Title I of the ADA any accommodation to the employee is supposed to be "reasonable." What is "reasonable" relates to the size of the business. The more dollars taken in by the business, the higher the obligation to provide the services needed by the disabled person.

Under Title II of the ADA, for state and local government programs, a department director has to show "undue burden," or that providing an interpreter would in some way "fundamentally alter the program." This is very difficult to do for large government agencies. Under Title III of the ADA most private businesses open to the public must avoid discrimination by providing interpreters where they are needed for "effective communication" if they can "readily" afford to do so.

Doctors will frequently argue that they lose money on visits by deaf patients. That's not the test. The test is the total number of dollars coming into the doctor's office as compared to the dollars that are spent for interpreting services for that year. If a surgeon is making a half million dollars a year and he or she spends a couple of thousand dollars on interpreters, that should be "readily" affordable under the ADA rules.
As an aside, the Federal Government is not covered by the Americans with Disabilities Act, but is covered by Section 501 of the Rehabilitation Act, an older law which dates from 1973 and mandates the provision of “effective communication.” It is thus like the ADA, but at the same time it is weaker because it takes much longer to get enforcement in court. In this case, one may have to try to enlist the help of one’s congressional representatives, or plead with the Equal Opportunity office of the agency in question.

For example, I have a postal worker’s case filed under Section 501 of the Rehabilitation Act. He is saying, among other things, that they didn't provide an interpreter at the safety meetings. They didn't provide an interpreter for a disciplinary meeting. The only remedy here is to talk to an Equal Employment Opportunity counselor at the post office, and this has to be done immediately after a discriminatory event and before a deadline.

Deadlines must be followed in a case like this very carefully. If you miss any deadline, you are out of the process and can't bring a lawsuit later. My client started back in September 1995, following all the deadlines and going through all of the steps of the postal service investigation to a hearing nearly three years later. Now, if we are lucky, we might get the EEOC to decide the case some time in 1999. So I repeat, if you miss one single deadline, you are out; you can't come back into it and can't go to court. The Federal EEO process is far more difficult than the enforcement mechanisms in the private sector under the ADA.

But getting back to the ADA, remember that you are entitled to an interpreter who can transmit information “effectively.” That means you are entitled to someone who has some kind of certification as an interpreter at a particular level of skill, not just someone who knows a few signs. The interpreter should also be a neutral person who has no stake in the conversations being interpreted.

There may be times when you bring your own interpreter, and here you take a risk. Ideally, you want the responsible party under the ADA to pay for it. However, the provider has to agree in advance before that can happen.

Questions will come up about what is covered by the ADA and what is not. Businesses, as we have seen, are subject to the ADA, but so are associations such as teachers might have. If an association offers courses to the public, for example, nonmembers as well as members, then they are a “public accommodation” under the ADA. As such, they are obliged to provide a means of “effective communication” to those with hearing loss who attend their public conferences.

Schools and colleges are also subject to the ADA. In Kansas, we had a young oral deaf man from Wichita who was brilliant. He relied on Signed Exact English. He went to Kansas State University (KSU). The first year or so, KSU wouldn't provide him CART services. His dad and I went to work on that – and between the university and the vocational rehabilitation system the cost was split. This man graduated with a degree in physics, another degree in engineering, a third degree in English, and he was named a Rhodes scholar in January 1998.

Now there is also the issue under the ADA regarding whether an employer has an obligation to find out if reasonable accommodations might be needed. Or is the individual with hearing loss responsible to tell an employer what is needed?

There are rules of law on that subject. One is that employers are not obligated to accommodate disabilities of which they are unaware.
My practical advice is this: You are looking for a job. You will go for an interview. If you have a significant hearing loss, you will probably need an accommodation at the interview. It doesn't make any sense to hide the fact you have a hearing loss. If you need an accommodation at the interview, you should say, "I need CART, an interpreter, or whatever." We need to be prepared – as the individual with the disability – to say what we will need before we proceed. It doesn't do you any good to try to fool the employer into thinking you don't have a hearing loss. They will come back later and say, "You never told me." Then you don't have any basis to sue because they did not know. You don't gain anything by trying to hide your need for accommodations.

Also, there are some things that an interviewer is prohibited from asking in a job interview. One web site for the EEOC has 150 pages of guidance on the questions that you are not supposed to be asked in an interview. Unfortunately, it is very complicated. Generally it is best to volunteer to take a hearing test from an outside professional. Don't volunteer to have it done by the office where you are planning to go to work. Volunteer to provide your medical information. Volunteer information from people who know you and what your communication capabilities are. Educate the employer about what your needs are. If you surprise the employer later, it won't help your job situation. There are some good employers out there. The Vice President of our Chamber of Commerce has seven deaf relatives. That's where you want to work. Lawsuits are not recommended for keeping blood pressure down.

The 911 system is also an important part of our lives. The U.S. Attorney in Washington has told all of the local U.S. Attorneys to monitor the 911 systems. Some investigations have been completed in places like Pittsburgh, Tulsa, and San Francisco, to update 911 with proper training and equipment. The telephone company representatives should know how that equipment works because there are newer versions that are much better than the old.

One health case that was recently settled and which involved hearing loss issues was one involving the hospitals in Connecticut. The National Association of the Deaf has launched a campaign to make sure that none of us suffer because of hearing loss when we are in the hospital and, partly as a result of this, the hospitals in Connecticut settled a class action for lots of money. The hospitals agreed to post notices that they will provide interpreters and other auxiliary aids and services in the hospital and arrange for statewide 24-hour referral service for interpreters. They also agreed to train their staffs to deal with deaf people.

Many more questions can be answered by going to the ADA web pages. The main one is the U.S. Department of Justice, Civil Rights Division, ADA Home Page. If you are interested in tracking current cases under review, you can access an entire set of Federal Court cases. Simply plug in words like ADA and get all the ADA cases.

Try a commercial service like Lexis or Westlaw. Most law schools have a wonderful computer lab available to them which might be available to you, as well as many very good text books. Last but not least, virtually every public library around the country, has a set of wonderful ADA pamphlets that cover many practical situations.

Many employment cases are settled because most people in employment situations find they can't afford to try to bring a case involving a deaf or hard of hearing person. Employment cases have a damage ceiling on them of $300,000. Many lawyers don't like that, as they are paid only if they win – 3 or 4 years after the fact. I practice in a community with 1,400 lawyers. Out of that number, maybe 20 would even consider taking a civil rights case for an individual. There are 50 or 60 that are more than happy to represent companies and get paid from the start. The economics of doing
civil rights cases for individuals are poor. There are also major risks to future employment if one
sues an employer.

Is anyone trying to repeal or modify the ADA? Not in any serious way. Most of the politicians on the
right and left are kind of content to leave it alone. The only bill introduced recently would deprive
prisoners in the various prison systems of the protections of the ADA.

Author's Note: Remember, this is general information, not specific legal advice. You will need to
see your own attorney for specific legal advice.
INTRODUCTION

This paper will discuss an agency of the federal government that is very important to all persons who are either deaf or hard of hearing, namely, the Federal Communications Commission. In the paper, we will try to answer four basic questions related to this agency.

1. What is the Federal Communications Commission (FCC)?
2. What has the FCC done in the past that has significantly affected the lives of people who are deaf or hard of hearing?
3. What are some issues that the FCC probably will consider in the future that will have an impact on deaf and hard of hearing people?
4. How can deaf and hard of hearing consumers participate in the regulatory process of the FCC?

In answering these questions, we hope to show the importance of the FCC in the lives of persons who are deaf or hard of hearing, and how such persons can advocate for telecommunication policies that will enhance their well being.

STRUCTURE AND FUNCTION OF THE FCC

What is the Federal Communication Commission? The FCC is an independent regulatory agency of the federal government. It reports directly to the United States Congress. While the Congress is its boss, the President actually appoints its members. It is a relatively old agency as Federal agencies go. It was created by the Communications Act of 1934, so the agency is now about 65 years old. The basic charge of the FCC is to develop and implement policy concerning interstate and international communications by radio, television, wire, satellite and cable. Its jurisdiction covers the entire United States, the District of Columbia, and all U.S. possessions. Its mission is basically twofold.

First, it encourages competition in all communication markets; and second, it's there to protect the public interest. Of course, in order for the FCC to protect the public interest it needs to know what your interests are.

What does this important federal agency actually look like? Structurally, it is a rather simple agency. At its head sit five commissioners. The commissioners are all appointed by the President, and then they must be confirmed by the U.S. Senate. The commissioners serve staggered five-year terms, and the chairman of the FCC is designated by the President.
Looking at the political composition of the FCC, no more than three of the five commissioners can be of any one political party. So in reality, what you will always find is three commissioners from one of the two major political parties, and two from the other major party. Of course, the majority of three are usually from the President's political party.

Last, we might mention that anybody who serves on the FCC can't have a financial interest in any of the Commission's affairs.

Having looked at the general structure of the Commission, one might wonder who the five people are that actually sit on this important agency, and really make the rules and regulations that sometimes seriously impact the lives of people who are deaf or hard of hearing. The chairman of the FCC is William E. Kennard. Chairman Kennard is a Democrat, and was the General Counsel of the FCC from 1993, until his appointment to the Commission in 1997. His term on the Commission expires in 2001. Another Democrat on the FCC is Susan Ness. Commissioner Ness previously served as Vice President and Group Head of the Communications Industries Division of American Security Bank. Her term expires on June 30, 1999. The other Democrat on the Commission is Gloria Tristani. Prior to joining the FCC, Commissioner Tristani served on the New Mexico State Corporation Commission, where she was the first woman elected to that office. She was named one of the nation's 100 most influential Hispanics by Hispanic Business Magazine in 1996. Her term on the FCC expires in 2003. The two Republicans on the Commission are Harold W. Furchgott-Roth and Michael K. Powell. Prior to joining the FCC, Commissioner Furchgott-Roth was the Chief Economist for the U.S. House Committee on Commerce. His term ends in 2000. Commissioner Powell was previously the Chief of Staff of the Antitrust Division in the Department of Justice. His term on the FCC expires in 2002.

The FCC is composed of two kinds of sub-entities called “bureaus” and “offices.” The FCC is composed of six bureaus. The Mass Media Bureau regulates radio and television broadcasting. The Cable Services Bureau regulates cable TV. The Common Carrier Bureau regulates the telephone and telegraph industries. The Compliance and Information Bureau investigates complaints and violations of the rules and regulations promulgated by the FCC. The Wireless Telecommunications Bureau is a newer bureau that regulates the wireless industries, including cellular telephones and pagers. Last, the International Bureau regulates international and satellite-based communications.

In addition, there are eleven offices in the FCC. The Office of Engineering and Technology evaluates technologies and equipment. The Office of Plans and Policy develops and analyzes policy proposals. The Office of the General Counsel reviews legal issues and defends FCC actions in court. The Office of the Secretary oversees the filing of documents in all FCC proceedings. The Office of Public Affairs distributes information to the general public and the media about FCC procedures and decisions. The Office of the Managing Director manages the FCC internal administration. The Office of Legislative and Intergovernmental Affairs coordinates FCC activities with other branches of government. The Office of the Inspector General reviews all FCC activities. The Office of Communications Business Opportunities provides assistance to small businesses in the communications industry. The office of Administrative Law Judges adjudicates disputes. The Office of Workplace Diversity ensures equal employment opportunities within the FCC.

From the perspective of people who are deaf or hard of hearing, one of the most important parts of the FCC is the Disabilities Issues Task Force (DITF). That task force is an internal FCC task force, created by the agency itself, and dedicated to ensuring that FCC policies and actions promote access to telecommunications equipment and services by all individuals with disabilities, not just persons who are deaf or hard of hearing. This is a relatively new task force. It was formed in 1995, by Reed Hundt, who was then the Chairman of the FCC. Each of the six bureaus and
eleven offices has a representative on the DITF. In addition, the chair of the FCC also sits on the DITF. So there are a total of eighteen people serving on the Disability Issues Task Force. The Director of the task force is Merrill Icove, and the Assistant Director is Pam Gregory (pgregory@fcc.gov).

**FCC RULE MAKING PROCEDURES**

Now that we have discussed the general structure and composition of the FCC, we want to briefly outline how the FCC works. One of the things that often starts an FCC action is when the U.S. Congress passes a law and gives the FCC the responsibility for developing specific regulations for implementing that law. For example, when the Congress passed the Americans with Disabilities Act of 1990, (ADA), it gave the FCC responsibility for developing the regulations to implement Title IV of that Act. In addition, at any time the FCC may receive a “Petition for Rule Making” from either a consumer group or a group from industry in which it is asked to either modify old rules or adopt a new rule in any of the areas that it has responsibility for regulating. For example, a deafness-related organization may petition the FCC to modify its rules regarding the percentage of programs on television that must be captioned. The organization may feel that there are not enough programs captioned on television, and that they want every program captioned.

Usually after a Petition for Rule Making is submitted to the FCC, the general public then has thirty (30) days to submit “comments” regarding that petition. Sometime after the end of the period for comments, the FCC may issue an order disposing of the petition, in effect saying that the petition requests something that is obviously not in the public interest, or is undesirable for some other reason. On the other hand, the FCC may issue what is called a “Notice of Inquiry” (NOI). When they do so, they are in effect saying that there is something in the petition worth thinking about, and they want to ask the public what it thinks about the issue. The FCC asks the public by announcing this Notice of Inquiry. In an NOI, the FCC simply asks a series of questions, basically seeking opinions and feedback from the general public about different components of the issues involved.

After the NOI is publicly announced (by publication in the Federal Register), people usually have a period of thirty (30) days in which to provide their opinions by submitting “comments” in response to the NOI. After the comments are received, often the FCC will allow a second period of time for what are called “reply comments.” During this period you have an opportunity to reply to comments that were submitted by other people or groups during the comment period.

Following this period for reply comments, the FCC may issue an order explaining why it is taking no action. Usually, however, the FCC will issue what is called a “Notice of Proposed Rule Making” (NPRM). When an NPRM is issued, the FCC indicates the rule that they are probably going to adopt, and again asks for opinions and feedback from the public regarding that proposed rule.

Then members of the general public again get an opportunity, which is usually thirty (30) days, to send in “comments” telling the FCC what they think of the proposed rule. Thereafter, there is often again an opportunity to submit “reply comments.” Following this, the FCC may sometimes issue a “Further Notice of Proposed Rule Making” (FNPRM) in which they seek further feedback because they have something that they’re not sure about or the comments or reply comments are ambiguous and need clarification. After they issue an FNPRM they again allow periods for “comments” and “reply comments.”

Sometime after the periods for comments and reply comments have ended, the FCC will issue a “Report and Order” (R&O) which specifies their final rule. That can be followed by a someone submitting a “Petition for Reconsideration,” and that may be followed by a “Memorandum Opinion
and Order." The original Petition for Rule making, NOI, NPRM, "comments," and "reply comments" are all integral parts of the FCC's process of regulatory rule making. Summaries of all their notices are printed in the Federal Register, and are also available on-line at the FCC web site http://www.fcc.gov.

One shouldn't get the idea that this is a fast process. This can take a long time to go through all the stages, often many months and sometimes several years. Although at times it is a very lengthy process, it does allow several opportunities for members of the general public to provide input into the process and potentially affect its outcome.

**HISTORICAL IMPACT OF THE FCC AND PERSONS WHO ARE DEAF OR HARD OF HEARING**

We now want to present a brief overview of some of the past pieces of legislation and FCC regulations that have impacted the lives of people who are deaf or hard of hearing. The role of the FCC in promoting telecommunications access dates back to 1976. In that year, the FCC set a new technical standard to allow for the transmission of closed captions for television programming. They also enacted rules requiring television broadcasters to transmit emergency messages in a visual format.

However, government activity to promote telecommunications access really began in earnest in the 1980's. It began on the state level with many of the states setting up statewide relay services and equipment distribution programs to disseminate TTYs, telebrailers, and volume control phones. This was several years before the passage of the Americans with Disabilities Act. California led the way, quickly followed by Illinois and New York, and then by many other states. Right now, there are about 25 states with equipment distribution programs.

These early efforts by the states soon resulted in pressures for access policies on a nationwide basis. During the 1980's and 1990's there were several different pieces of federal legislation that involved telecommunications access. On a national level, leaders of the deaf and hard of hearing communities really led the way in making telecommunications accessible. They were the initial advocates for federal legislation.

The first law that was passed at the federal level was the Telecommunications for the Disabled Act of 1982 (P.L. 97-410, codified at 47 U.S.C. sec. 610). This particular law allowed the states to require telecommunications carriers to continue to provide subsidies for the equipment distribution programs. Probably of more importance, the act also began to set forth requirements for hearing aid compatibility of wire line telephones. It established standards. Namely, that the law required phones in certain places of employment, in hotels and motels, and in health care facilities had to be hearing aid compatible. In addition, the law established the way in which phone equipment had to be hearing aid compatible.

The next law came about in 1988, namely the Hearing Aid Compatibility Act of 1988 (P.L. 100-394, codified at 47 U.S.C. sec. 610). This law required all so-called "central telephones" and all wire line telephones manufactured in the United States, imported for use in the United States, or sold within the United States after August 16th, 1989, had to be hearing aid compatible. There were, however, a number of exemptions, such as mobile phones, phones used for public radio services, and cordless phones (which were exempted until 1991).

Also in 1988, the Telecommunications Accessibility Enhancement Act (P.L. 100-542) was signed into law. This legislation did not go to the FCC for the development of implementing regulations, but it required that federal agencies establish their own relay services. They have done that and
it enables deaf or hard of hearing people to communicate with employees of federal agencies and federal employees who are deaf or hard of hearing to communicate with hearing persons in the general public.

Another piece of legislation that was passed in 1988, was the Technology Related Assistance for Individuals with Disabilities Act (P.L. 100-409, codified at 29 U.S.C. sec. 2201). Again, this legislation didn't go to the FCC for the development of implementing regulations, but it has impacted the lives of all persons who are deaf or hard of hearing. This act provided money for federal grants for the establishment of the Technology Assistance Programs (TAP) in all of the states. Those programs provide people with disabilities with information, technical assistance, and training concerning accessible technology.

Then we entered the 1990's, and the Americans with Disabilities Act of 1990 was signed into law (P.L. 101-336, codified at 42 U.S.C. sec. 12101 et seq.). There were several sections within that act which impacted telecommunications access. First, Title IV of the ADA required that all common carriers who provided voice telephone services to provide both intrastate and interstate telecommunications relay services. These relay services were to provide “functionally equivalent” telecommunications services for people who couldn't otherwise use a conventional telephone. The regulations implementing Title IV of the ADA were developed by the FCC, and those regulations became effective on July 26, 1993. In addition, Titles II and III impacted telecommunications access for people who are deaf or hard of hearing, although to a much lesser extent.

Then we move to a totally different area, the whole area of captioning television programming. With the passage of the TV Decoder Circuitry Act of 1990 (P.L. 101-431, 104 Stat. 960, FCC Rules found at General Docket No. 91-1, FCC 91-119, 38151), for the first time, manufacturers of TV equipment were required to build in access for persons who were deaf or hard of hearing. In particular, that law required that every television set with screens of 13 inches or larger either manufactured or sold in the United States after July 1, 1993, had to be capable of displaying closed captions. They had to have the decoder circuitry built in to the set, as opposed to relying on external decoder boxes that had been used up until that time.

As we have indicated, there are different procedures within the FCC. Another procedure that we haven't discussed is when the FCC asks all the parties interested in an issue to meet, try to work out their differences regarding that issue, and propose a rule that is acceptable to all. This is in contrast to the FCC coming up with their own proposed rule regarding the issue. This procedure is called a “Negotiated Rule Making” and during 1995-1996 there was a negotiated rule making regarding hearing aid compatible telephones. This FCC negotiated rule making involved consumer organizations for people with hearing loss (such as the National Association of the Deaf, the National Center for Law and the Deaf, Telecommunications for the Deaf, Inc., Self Help for Hard of Hearing People, and the New York League for the Hard of Hearing), the Hotel and Motel Association, employers, home care facilities, and we all worked together and came up with a number of agreements. The agreement defined what “essential telephones” were, and required that essential telephones in the workplace, confined settings (hospitals, nursing homes, and other health care facilities), and hotels and motels would have to both be hearing aid compatible and incorporate volume controls. Furthermore, that rule making resulted in the mandate that as of January 1, 2000, all telephones that are either manufactured in the U.S. (except for export) or sold within the U.S. will also have to have volume controls on the handsets.

The next piece of legislation that passed was in 1996; and we would suggest that this is probably the most important piece of legislation for all people with disabilities in the area of telecommunications access. Within the Telecommunications Act of 1996 (P.L. 104-104, codified
at 47 U.S.C. sec 151), there were two different sections that will impact people who are deaf or hard of hearing. The first is Section 255, and that requires all manufacturers of telecommunications equipment and providers of telecommunications services have to make their products and services accessible to and usable by individuals with disabilities if it's readily achievable to do so. And, if they're not able to make the equipment or services accessible to people with disabilities, then they have to make them compatible with accessible peripheral devices, if it is readily achievable to do so.

As of now, the FCC has received comments and reply comments to their Section 255 proposed rule making from all of the interested parties, including both consumers and industry. The FCC is now reviewing all of that information, and interested parties have an additional opportunity to affect the FCC's final rule through what is called an *ex parte* presentation. In non-restricted proceedings, anyone can go to the Commission after all comments and reply comments have been filed and try to add data and/or arguments to support their position on the issue(s) in question. In order to keep all parties informed, there must be public notice posted by the Commission's secretary of all *ex parte* presentations. The hope is that the FCC will have rules developed regarding Section 255, by mid-1999.

The second section in the Telecommunications Act of 1996 that affects persons who are deaf or hard of hearing is Section 713. This section requires that video programming be closed captioned unless it would be an undue burden, and there are quite a number of exceptions that have been outlined in the regulations. The FCC also is requiring that there be an examination of the use of video description for television. Rules from that section are also available from the Federal Communications Commission.

**PROBABLE FUTURE FCC ISSUES OF IMPORTANCE TO PERSONS WHO ARE DEAF OR HARD OF HEARING**

There are numerous issues that the FCC will probably consider during the next few years that will impact the lives of people who are deaf or hard of hearing. As an example, an issue that consumers and industry have been working on for a number of years is the ability to make a coin-sent-paid call through TRS (Telecommunications Relay Service) using a public pay phone. In developing their regulations for the implementation of TRS under Title IV of the ADA, the FCC had mandated that relay services were to be able to handle all types of incoming calls including coin-sent-paid. That regulation was to become effective in 1993. Before the date it was to become effective, the FCC suspended the rule in response to industry arguments that it was not technically possible to implement the rule at that time. In 1995, the FCC extended the suspension until 1997, and approved an interim alternative plan which included free local calls through TRS from pay phones and the acceptance by TRS of either calling cards or prepaid phone cards. The suspension of the rule was again extended in 1997, for a year; and in 1998, it was extended another year. Currently, the suspension expires on August 26, 1999, so it is certain that we will hear more about this issue from the FCC in the future.

Another issue which has been addressed by the FCC recently, and which probably will receive more attention from them in the future, is the issue of three-digit dialing for nationwide access to relay services. This would enable a person to dial only three numbers to access the telecommunications relay service in their state, and those would be the same three digits in all states. So instead of having to dial 1-800 plus seven more numbers, a person would only have to dial three numbers. Representatives of the deaf and hard of hearing community began advocating for three-digit access back in 1992. Finally, in February of 1997, the FCC ruled that the number "711" would be reserved for TTY access to relay services nationwide, and concluded that it should
be implemented within two years. Unfortunately, there are still unanswered questions regarding the specific implementation of that ruling, so the FCC will be discussing this issue again in the near future. The good part of it is that a number of the telecommunications companies have jumped ahead of the FCC a bit and have either already implemented the three-digit access system, or will do so in the near future. For example, a person can access TRS in Hawaii by simply dialing 711 now, and not too long ago, Bell Atlantic announced that they would implement 711 access throughout their region in the near future.

The FCC will certainly need to revisit their rules regarding telecommunications relay services from time to time in the future. For example, in 1997, the FCC issued a Notice of Inquiry concerning the improvement of relay services. That NOI asked for comments regarding such things as Video Relay Interpreting (VRI), speech to speech relay, multilingual relay services, and improving quality standards for Communication Assistants (CAs). That NOI was followed in May 1998, by a "Notice of Proposed Rule Making" (NPRM) for the improvement of relay services. As of this writing, no final rule for the improvement of TRS has yet been issued by the FCC, so more will be heard from them regarding this area in the near future.

It seems quite probable that sometime in the future the FCC will be asked to consider the mandatory incorporation of voice-to-text technology into TRS. A lot of late-deafened adults and hard of hearing people are going to be advocating very strongly for the provision of true realtime telecommunications relay services through the incorporation of speech-to-text. That question in one form or another will end up on the FCC's agenda.

The accessibility of web sites is another issue that somewhere along the line will end up on the FCC's agenda, especially the Disability Issues Task Force. If you are a deaf or hard of hearing, you may well be getting tired of not hearing the audio dialogue that occurs at numerous web sites. And if you really want complete access to those web sites, that's an issue that you ought to take upon yourself to get involved with, and advocate for a rulemaking concerning web site accessibility.

Another issue that the FCC may become involved with in the future is the desire of some to mandate the inclusion of a new international standard in all modems which would allow computers sending ASCII code to communicate with TTYs sending Baudot code, allow TTYs sending Baudot code to communicate with TTYs sending ASCII code, and allow TTYs from any country in the world to communicate with TTYs in any other country. At present there are numerous different standards used for telephones in various parts of the world, and our technologies often can't talk to each other. In the recent past, Telecommunications for the Deaf, Inc. was involved in promoting the development of a new modem standard which is called V.18. That standard would allow any computer to talk to any TTY anywhere in the world, and any TTY to talk to any other TTY. Once a representative from industry comes forward and actually manufactures and markets the V.18 modem, consumers will start buying it and will want it to be in every computer that gets sold - just like today the decoder chip is in every television set that's manufactured or sold in the United States.

For some time now, manufacturers of cellular phones, deaf and hard of hearing consumer organizations, and TTY manufacturers have been discussing the issue of how to make analog TTYs and digital cellular phones compatible so that communication is clear. In particular, those discussions have been required by the FCC in order to ensure TTY accessibility of 911 emergency centers by deaf and hard of hearing people using cellular phones. And this issue will undoubtedly receive more FCC attention in the future.
Another issue of concern to persons who are deaf or hard of hearing is what has become known as "multivendoring" or "consumer choice" with respect to telecommunications relay services. Some consumers feel that they should have a choice on a call-by-call basis of the TRS provider that they use. Maybe one TRS provider offers services that your state designated TRS provider does not offer. California is an example of one state that presently has multivendoring, but many consumers are looking to the FCC and saying, "Consumers would like to have freedom of choice in all states." Admittedly, there are a lot of pros and cons regarding this issue, but certainly the FCC will be asked to rule on the issue in the future.

PARTICIPATION IN THE FCC RULE MAKING PROCESS

Some people might say that in order to understand the FCC procedures and influence FCC decisions you need to either go to law school, be a lawyer, or hire a lawyer to help you. That's simply not true. You may just want to tell the FCC how you feel about different things that influence your life, especially if you are a late-deafened person that had certain things growing up and then lost them. As a late-deafened person you can understand what it feels like to both "have it" and "not have it." So, if you have an opinion regarding any FCC issue, let them know your thoughts. Your opinions are very valuable to the FCC, and they want to hear about them. They want your active participation and consumer input.

It should also be pointed out that while the FCC reads your comments as they may bear upon a particular policy issue in question, people in the telecommunications industry read your comments as well. They provide good input to industry, and give industry a better sense of how consumers feel. Often the FCC and industry pretty much know where they are going to come down on issues, but the input from consumers is always a wild card. Consumer comments often give industry and the FCC new insights, and they sometimes can carry more weight and power than the things that industry says alone. So consumer comments can be very important in educating both the FCC and industry.

The first thing that you have to do in order to participate in the FCC rule making process is educate yourself. You need to acquaint yourself with the rule making process and the rule making issue. We have already talked about the process, so we won't go over that again. In order to familiarize yourself with the rule making issue(s) you can read the FCC press releases, the public notices (NOI), and the proposed rule making (NPRM). You need to read to be sure that you understand what the FCC is proposing.

One way to monitor what FCC issues might affect you is to check the Disabilities Issues Task Force information on the FCC web site http://www.fcc.gov/dtf. There is a lot of free information from the FCC on the web, so if you have access to it that's wonderful. For those of you that have access to the FCC web site you can get what's called the FCC Daily Digest. You subscribe to it, and it comes to you via e-mail automatically. You don't have to take the time to visit the FCC web site after you once subscribe to the Daily Digest. To subscribe to the Daily Digest, send an e-mail to subscribe@info.fcc.gov with no "subject" line and a one-line message in the text which says "subscribe digest Yourfirstname Yourlastname" where "Yourfirstname" is your first name (such as "Roy", or "Pam") and "Yourlastname" is your last name (such as "Miller", or "Holmes", or "Ransom").

If you don't have access to e-mail, then you can receive the Daily Digest by fax. You can access the fax on demand system of the FCC by calling 1-202-418-2830. The Daily Digest is really easy and worthwhile to use. You just scan it up for a minute or two every day, and read the highlights of what the FCC is doing.
If you want extensive information about the FCC rule making procedures, you can contact the FCC and request a copy of the Disabilities Issues Task Force Handbook. The handbook will give you information concerning all of the different things that we have talked about in this paper. The phone number of the FCC is 1-888-835-5322 (TTY) or 1-888-225-5322 (Voice), and the address of the FCC is as follows:

Federal Communications Commission, 445 Twelfth Street, S.W. 12th Street Lobby, TW-A325 Washington, DC 20554

For those of you who can access the web, and are interested in monitoring issues that affect people who are deaf or hard of hearing, you can either start by looking at the FCC homepage http://www.fcc.gov or go directly to the Disabilities Issues Task Force page http://www.fcc.gov/dtf/.

You can also visit the web page of the National Association of the Deaf Telecommunications Committee http://www.48i.com/nadtco/ for information about FCC activities related to deafness.

Another source for authoritative information regarding FCC proposed rule makings is, of course, the Federal Register. You have to know the volume and number (or date) of the Federal Register that you want to examine, but you can get that information in the Daily Digest. You can access the Federal Register on-line, and download the desired information to your computer.

In sum, there are many ways that you can contact the FCC to educate yourself about their proceedings. You can reach them by snail (surface) mail, e-mail, fax, telephone (toll free), or on the web.

Another way to educate yourself about FCC issues is via on-line chats or newsgroups. Sometimes there are consumer groups that have a common interest in telecommunications, and they get together on-line and discuss different issues. It can be a very interesting way to learn about different telecommunications issues, and where various people stand. Sometimes there can be brief discussions of telecommunications issues on LISTSERVs, such as "DEAF-L" deaf-l@siu.edu or "Beyond Hearing" beyond-hearing@acpub.duke.edu.

Your participation in FCC rule making proceedings requires two or more different steps. First, as we have said, you will need to educate yourself regarding the issue(s) involved and the proposed FCC action. The next step is that hopefully you will submit your comments regarding that proposed action. Next, you may want to review the comments of others regarding the issue(s) in question. And finally, you may want to submit reply comments to any of the other comments which have been submitted and with which you disagree.

The FCC has recently made it very easy for a person to participate in their rule making process. They now accept comments and reply comments at their web site via their Electronic Comment Filing System (ECFS). If you don't have access to the web, you can also send in comments via e-mail. Some of us all too often do our thing at the last minute, and mailing a package by Federal Express simply won't get it there in time. But now you can go to the FCC web site and submit your comments electronically. In any case, when submitting comments you have to be sure to put down the docket number so they know which rule making proceeding you are commenting on.

**CONCLUSION**

In summary, we want to leave you with several thoughts. First, the Federal Communications Commission has made many regulatory decisions which have historically had a major impact on the lives of persons who are deaf or hard of hearing, and the FCC will continue to do so in the
future. Second, in order for the FCC to do the best job of protecting the public interest, it needs and wants to receive your opinions regarding the many issues that it considers. Third, as a person who is deaf or hard of hearing, you owe it to yourself and others like you to pay particular attention to this important federal agency. Educate yourself regarding the issues that the FCC considers. Monitor their proposed rule makings for the issue areas that can tremendously affect the lives of persons who are deaf or hard of hearing. And then participate in the relevant FCC rule makings with strength, knowledge and conviction. Let your voice be heard, so as to ensure that the federal government continues to choose telecommunications policies that will enhance the lives of persons who are deaf or hard of hearing.
I want to tackle the subject of consumers and how they experience technology and telephony both before and after deafness. But first a pop-quiz: who knows what PAL means? PAL is a very useful tool that we use at Sprint to run meetings.

P stands for “purpose.” The purpose of this panel is to, as I said, get a consumer perspective on what it was like using telephones and technology before becoming deaf, and then how that is changed after deafness. It’s important to realize that this kind discussion might not happen for other populations with hearing loss. For example: those who were born deaf. They are not going to miss using telephones. Or for those who are hard of hearing from birth or very early in their lives. So it’s a very specific experiential process with telephones and technology that we will discuss today.

The A in PAL stands for “agenda.” For the agenda of this meeting, we have five questions that I have asked each of the panelists to address.

1. First, each of the panelists will address what experiences they had with telephones and technology before they became deaf.

2. Second, they will tell us how those experiences have changed after they became deaf.

3. Third, they will share with us what adaptations or adjustments they have made as a result of these changes in order to remain functional in our technological world.

4. Fourth, we will be talking about the impact that those changes have had on significant others, friends, family, and co-workers.

5. Fifth, they will share with us their hopes, dreams, and aspirations for telephony and technology in the future.

So that is the agenda.

Finally, what is the L in PAL for? The “length” of the meeting. We have exactly one hour and 15 minutes. Each panelist has 12½ minutes to talk.

Lorie Shepard:

I didn’t become deafened until about 7 or 8 years ago. In my mind, it was a very quick process. But what I remember about the telephone and technology before I lost my hearing
was that I didn't think about it. I simply picked up the phone and I made a phone call. I sat
down and watched television. I never thought about people with hearing loss.

Then my whole life changed. I avoided the telephone. I would do anything in the world not
to use the telephone. I became very dependent on others. I lost my sense of privacy. This
for me was really an awful time. I actually did not know about relay service for probably a
year. I had what I call "that gray zone" or "the winter of discontent," when I was just totally
lost. The adaptations I used: I had a fax machine and I encouraged everyone I knew to get
a fax machine. It was my way of hiding my deafness. I would say, "Look, you live in another
time zone. It would be easier if you just get a fax machine and I can send you a message
and it's no big deal." I still use a lot of adaptive technology. I have e-mail. I have a WyndTell
pager. I have a fax machine. I have children that sometimes, I hate to admit, I actually will
use them to help me out. But now, I'm becoming stronger in insisting that people who start
talking to my children, asking them to talk to me directly.

ALDA has helped me a lot. This morning we, the four of us, met and talked a bit about this.
It's very hard to admit that a lot of my hearing friends have disappeared. They no longer
communicate with me. You know, I get the ritual Christmas card and that's about it. When
I've tried to explain to some of my best friends how simple the relay call is, these are people
who have extremely high levels of education and tremendous jobs, you'd think asked them
for rocket technology, that was asking them to do something incredible. In fact, I was just
asking them to dial one additional number.

In my mind, what is the big deal? In their minds, it's a slow, painful, agonizing thing. They
don't like the idea of having this third person listening in. To them, it's an invasion of privacy.
To me, it's a way of life. That's the way it happens. I've accepted that. I have accepted the
loss of what I consider a lot of my privacy.

My children are better about relay than anyone else in my family. Now my husband refuses
to make relay calls. He will send me a fax. He will use my WyndTell pager. He will call the
children and ask them to please tell your mother to . . . whatever.

I think that has been probably the most painful part of losing my hearing. It's, in a sense,
losing some of my family. I have actually not talked to my brother in three years. I got to the
point where I just refused to call other people – to always be the one making contact. I feel
that communication is a two-way street.

My hopes and dreams for the future: I want the TTYs to disappear. I want to have like direct
connect in that if someone was calling me, it would just automatically go to either a relay
service or a voice recognition, a text based program, that it would become totally
transparent. My dream of technology, where you know I would be holding something,
maybe similar to the WyndTell pager, with speech recognition, and anyone could talk to me.
It would transform that speech into text.

David Coco:

Before I start, I need to tell you my experiences about becoming deaf. They are different
because I have progressive hearing loss. So the idea of switching from before and after is
like a slow gradual change in hearing. I always think of myself as like slipping off a
mountainside. For a long time, I was holding on to a branch. Finally, about 12 years ago,
I decided to let go and I decided I wouldn't use the phone in voice mode anymore. It's really
been one of the most significant decisions in my life, because, before that time I spent
tremendous amounts of energy, effort, and emotion, trying to understand what was going on the phone. I kind of degraded from talking with everybody to being able to talk to just my family.

I made a decision one day and didn't tell anybody else. I went home and I said, "I think I'm going to give up the phone." And my wife goes, "Thank God!" I never realized how my problems impacted other people. I just thought it was painful for me to use the phone.

Overnight, I went from making 20 to 30 phone calls a day to starting to use the TTY. Twelve years ago we didn't have relay in Texas, and we had a volunteer relay service, which meant I had to wait sometimes an hour or longer to make one phone call. We had a limit — 3 minutes. You had to pack all your phone calls in the 3 minutes and you had to do it probably like late in the afternoon, when they weren't too busy. It was unbelievable.

Since that time, relay has developed into a real asset in my life, and I have developed a lot of tools. One is I use what is called three-line VCO. You look at the computer and you also talk at the same time. You use regular VCO.

My kids pick up the phone, they sit down, they talk with their friend, and they talk for an hour at a time. No effort at all. Then, when they put the phone down, I ask them, "What did you talk about? Who was that?" "Oh, nothing. We didn't talk about anything." I say, "No, you must have talked about something for an hour." They cannot remember what they talked about. . . . truly.

I thought about that this morning and last night, and what they are doing is they are developing a relationship. They are developing a deep bond with that person they are talking with.

I never have done that and I miss that a whole lot. Because when I get ready to make a phone call, I have a list. I'm going to ask this person A, B, C. I'm going to get this point. I'm going to get off the phone and I'll hang up. If I called a person, a friend, just to talk they would drop dead. It's not because I don't want to do it, I enjoy interacting with people, I enjoy talking with them, understanding what they are saying, but because of my experience the idea of talking about non-important things on the phone just doesn't exist inside of me.

That is the main thing that I miss from my days before, having used the phone even if I didn't understand what people said. If I called my friend, I felt like I was connected with them somehow when I was on the voice phone. When I'm on a relay call, I feel very disconnected. I feel like I'm talking to the agent, or this person is having to talk very slow.

So, those are the things that I miss that are very important to me. I think they are important to other late-deafened people also. It's hard to put them into words sometimes, because it's hard to ask for a better relay system that will help you develop a relationship. But if the relay system were to become more transparent, become easier to access, then I think that sort of achievement will be possible.

Heidi Adams:
I also have a progressive hearing loss. However, there have been two different times over the last 20 years when I've had a major drop. I used to use the telephone all the time. After I finished school, I lived here in Chicago, and my family was in Ohio. So, we communicated mostly by phone. I used the phone in the course of my job. It was just a way of life. I
maintained relationships – established and maintained relationships by telephone. There were a group of us professionals working in Chicago that ended up networking by phone for probably a year before we even met face-to-face.

The next two questions kind of blend together for me, because my loss was progressive and there wasn’t a sudden change. The first thing to go, of course, was the telephone. But I discovered those wonderful little amplifiers that you can slip over a handset, which meant that I could still continue to use any phone anywhere. They fit in your pocket. All you had to do was change the batteries once in awhile.

But there was a point at which that changed. Perhaps the most critical point for me was when I was working as a rehabilitation counselor. We had a very old phone system, but it was a wonderful phone system because it worked very well with a “T” switch. Over the course of several months, we got a new phone system, I think also my hearing had deteriorated to the point where I couldn’t use it anymore.

I would vacillate. The phone would ring, and I would reach for it. I’d think no, I don’t have to answer it yet. It would ring a second time. I’d say no. It’s only two rings. It was this kind of push/pull thing before I would pick it up.

The thing that frightened me most was having a major misunderstanding on the phone that would affect my customers, the people that I was serving. So finally one day I simply bit the bullet. But I was lucky. The timing coincided perfectly with the establishment of the relay system.

So I have always worked – I shouldn’t say always, but since 1989, I have worked in a very supportive environment. So it was not difficult at all for me to get a TTY in my office. I began using relay.

Another important technology, if we stray a little bit from telephones, but talk about communications access, is CART, Computer-Assisted Realtime Transcription services. That’s a major part of my life. Most of my working life is communication. I use the phone a lot in my job. I also used the fax for the while. I was known as the queen of the fax, as a matter of fact. But, captioning is also a very, very important part of my life.

We also have TV captioning and I think that too is very important. Dr. Davila talked about that this morning. These two things probably have changed my life.

In terms of those people who are important in my life – my mother, who died about a year and a half ago, struggled with her own hearing loss, and struggled with the issues of aging. She could get relay calls, but she never quite got the hang of making relay calls. Two deafened people trying to yell at one another over the voice system doesn’t cut it. We talked very little on the phone in the last couple years of her life. Fortunately, she was nearby so I could just make a short commute.

My children communicate with me in any way. We do use the voice phone, because they know how to communicate with me. They are patient with me. Once in a while my son will do things like when I will ask him to spell something, will say “P” as in psychology or something like that. But they also use relay and are adept at using relay. They also use the TTY. My daughter had a TTY in her dorm room that she used to communicate with me when she was in school. My son has made a science out of finding TTYs in every
transportation hub or public building that he can. I've gotten TTY calls from some very strange places.

My brother has finally gotten to the point – I think my sister-in-law nudged him along – he will leave messages for me on the TTY, but he prefers to yell at me over the voice phone. The yelling part is important, because the most disabling part of my hearing loss is my very poor discrimination. So I can hear stuff, but when he raises his voice, it distorts the signal even further. But still we struggle on. He does not like to use the relay system.

In terms of my friends, I think because my hearing loss is progressive, it's been sort of attrition over a long period of time. I'm narrowed down now to those people that I can communicate freely with by TTY or who see relay either as a challenge or don't seem to notice it at all. Now we come to the important part for me. In terms of relay, what is my wish list? Well, even beyond relay, my wish would also be a voice recognition system. I just think that would change all of our lives in a way that we wouldn't even recognize. We wouldn't remember the bad old days.

But what we have now is relay. Relay really works pretty well. But we can make it work better. As far as I know, no one has ever done a study on what makes a good relay call. Or, what makes for a really effective communication associate (CA) as a relay operator? Because I spent about 4 months logging every single relay call that I made and got at work – we were looking to see if a new service worked or not here in Illinois – I really got into this thing and decided that there is kind of a Gestalt. There are relay calls that work; and it's not directly related to the number of typos or the speed of the call. It's something beyond it. What makes a wonderful facilitator? Why do some of those calls, for people like me who use relay all the time, why do some of them seem so much more transparent than others? I want to know that. Further, I encourage any of you that have any access to any entity, whether it's private or public, that could do that sort of research, to tell us what that is.

I think the other thing is that we need to focus more on the other relay user. Any time you have two-way communication, you have two customers. We are only one of those two customers. How can we get the word out? How can we help other people, those people that we are communicating with, to see relay as being more mainstream, to simply see it as another way of communication? We have cell phones and wire phones and we have phones that look different. How can we make relay fit into that entire pattern?

Last, but not least, of course, somehow we need to keep making these things that we use, the special things, more cost effective.

Linda Mazzola:
I've been deaf for about 10 years. Since I was in the 12th grade till about my mid-30s, I was hard of hearing and I was able to use the phone with an adapter. Then, after my 30s, I became deaf, totally deaf.

There are two things I miss since I became deaf. One is music. Number two is using the phone. When I was able to use the phone, I felt like I was independent. I felt like I was able to control my life. I'm a nurse. So a phone is very important for me in my job. As I became more hard of hearing and then deaf, I couldn't do my job anymore, so I had to leave nursing.
Becoming deaf and unable to use the phone, I felt less independent. I feel more dependent on relay service or other people to help me make a phone call. So I feel like I have less control of my life.

Nowadays, I'm really behind the times, but I recently got a computer. E-mail has helped a lot in keeping me in touch with my friends and family.

I'm working now at a home for the deaf where we have staff interpreters, so that is what I use most of the time at work. I use staff interpreters, and I voice for myself. They sign to me what the person is saying on the phone. To me, that is the most — almost the best way to communicate — it brings me back to my hearing days when I could communicate directly, myself to the person. So I use interpreters. Last, I would use relay, only in an emergency. Even when using the relay service that we have in Massachusetts, I tend to feel very frustrated and fed up and I just don't feel like I have control of the situation.

Further, if I need to use relay at work, and I'm calling very important people, like doctors or hospitals, then I always have to make sure I repeat back to the doctor the medication, making sure that I have the correct spelling. Because sometimes the spelling that is coming through the screen is wrong or the relay operator might not understand what is being said.

Personally, I have lost a lot of hearing friends because of my not being able to communicate with them via the phone. I use the TTY a lot to communicate with my deaf friends, but I really use the relay service very minimally.

My immediate hope is to improve relay service and to make it be as clear as possible. I hope in the future that we can have that.

**Audience Member:**
I want to comment on something that Lorie said. Lorie, you were talking about the slow attrition of people who you believed you were important to, friends and family, when the telephone no longer became so easy to use. I have an interesting coda to that story. From August 1989, until January 2nd of this year, I was unable to use the voice telephone. What happened in January is, you can see, I'm using an implant. About February of this year, I called a member of my family, my stepmother, by voice phone. She said to me, "Wow! Now that it's easy to talk to you on the phone again, I'll be talking to you more often."

Well, if I wasn't important enough to take up her time when I couldn't use the voice phone, she is not important enough to take up my time now that I can hear again. That was the last time I spoke to her.

**Lorie Shepard:**
You know, the psychiatrists and psychologists would have a field day with this.

**Audience Member:**
She is a psychologist.

**Lorie Shepard:**
I understand a lot of what my family's frustration is and what my friends' frustration is. Because how many CAs do you get who can type faster than 45 words a minute? How many of us speak... at... the... rate... of... 45... words... a... minute?
Who wants to ask you about what you are doing? They don't want to know because they are going to have to wait ten minutes to get the rundown from me. Voice carry-over helps a lot. But, then, it's more putting the burden of the conversation on me. It reminds me of when I became deaf. In a sense I became like the conversation "dominator-ess." I would talk. Don't interrupt me. Don't ask me questions. Let me just tell you about my life, my work, let me tell you about my kids. I no longer really wanted to listen to what other people were saying because it was so hard. Again, you have that with relay in that the conversation is so slow and so hard.

Mike Ellis:

Anybody else on the panel want to address the issue? Question?

Audience Member:

I'm plain hard of hearing rather than late-deafened. But my question is: I hate the relay service, pretty much the same as you do. However, as we all begin using e-mail more and more, there has been an introduction of a thing called a chat client or an Internet chat client, which does allow you to go two-way using computers. A lot of these high functioning friends you all have lost with the atrophy of your hearing, don't many of them have computers? Don't any of them use e-mail? Couldn't you use the e-mail chat client approach be a solution, especially since it gets a middle person out of the way?

Heidi Adams:

Yes. They do have e-mail. I guess my feeling is, though, I think I'm kind of reflecting on the two comments before, is that if you are worth communicating with, you are worth, at least on occasion, using relay with. We are talking about staying in touch, about making plans to meet, about connecting. That's what we are talking about. So I guess my friends have narrowed to those, whether they have e-mail or not, who are at least on occasion willing to communicate with me through relay.

David Coco:

There are a few things about e-mail communications and chat rooms that really bother me, that don't give me what I need from the communication. One is the spontaneity. You are not able to grab that person. Sometimes they are busy, not able to get back.

The other thing is that there is an emotional disconnection when you are typing just with text. I use VRI and other video relay systems. I'm really becoming a believer in seeing people face-to-face. I think there is something transmitted between the people when you are talking on the phone and you are able to hear the inflections, or you are able to see the person's expression. We are just not able to put that in e-mail or in text. That is the part I miss. I think that is the part which makes the relationship important. I try now, when I have really good friends, to say, "Hey, e-mail is faster." But if I want to talk to you, I'll visit you or we will make a connection so I can see that person. For deaf people, that means a lot of traveling, but that is an important part that you can't discount.

Mike Ellis:

Next question? Yes?

Audience Member:

I wanted to say a comment and then a question. The comment is that relay service is wonderful. I think the more you use it, the more it becomes user-friendly and you feel comfortable with it.
The more I could do what David said and make it be a friendly conversation, not just the A, B, C, and the more they hear my voice with VCO, the more they are willing to answer. It really can be about the best means of communication. It certainly has freed my family when I use relay. It freed them up from having to repeat so often and be frustrated. It really takes the frustration out of my family's life.

My question goes to relay, or a comment on what I'd like to see happen, and that is Caller ID. I use it so I can recognize who my phone caller is. It's wonderful. Except when a relay call comes, and the technology is not there yet to make relay come up on the Caller ID, but if you wanted to know what is needed, I think that's a really needed thing to address, because it makes hard of hearing and late-deafened people more willing to pick up the phone and not wait for someone else to, because they would know it was a relay call.

Mike Ellis:
Comments from the panelists?

Linda Mazzola:
I don't know. I really feel like I cannot say that relay is wonderful. I feel that we need to work really hard to improve it. I expect high standard relay service, and I feel like we don't have that now. I feel like it's not right to have that kind of service. I think about when I was hearing, when I was able to pick up the phone and make a phone call. It's like I can't do it now. But still I want to be able to pick up the phone and dial relay and know who is answering the phone. I don't even know that the phone is ringing. I just get a fast GA. So, I'm like is someone there? Can I talk now? I mean, it makes me feel so stupid, and I feel like I'm just inadequate. I feel like we still need to work together and make sure our relay service is top notch.

Mike Ellis:
Yes?

Audience Member:
My wish list is that everyone had a phone called the Uniphone. It's a TTY and phone together. I use a Uniphone with a TeleLink. If I'm talking to someone who has the Uniphone and we don't hear, we can go from the voice to the TTY mode instantly. So, you can hear and type at the same time. This eliminates relay. You have direct communication.

If you still have a bit of hearing and you can make out voices, even inflections – when somebody is depressed, you can hear that – you pick these things up if there is a little bit of hearing. But, if you can't understand the voice, then you go from voice to type. So, if everybody had the Uniphone, you go from voice to text or simply text or whatever mode you want.

But, since I do have hearing left, I prefer to use the phone. I have relay – the TTY phone for when I can't understand a call. Sometimes I ask people to use relay. Like if you get a lot of phone calls from telemarketing people wanting to sell you something, and since I can't understand them, I ask them to use relay. So far, not one telemarketer has ever used relay.

Audience Member:
It's true. One case. Years ago, I was flying on Continental Airlines and they had a huge plane that they had to reduce to a small plane. They were asking people to voluntarily get
off the plane and offering compensation, getting free tickets to fly someplace else. When the man called, I couldn't understand him. I asked him to call on relay, and he did.

**Mike Ellis:**
More questions? We will close in about 15 minutes.

**Audience Member:**
Hi there. My name is Brandi, and I work with Mike at Sprint. I have a question for the panelists. I work with the telephone every day, and it's a big part of my job. I'm very lucky to have interpreters at work that help me. I do a lot of work that is required for business, and a major challenge and a concern for me is keeping up. I can see that many people I work with have telephones in their cars, they bring their cell phones out to restaurants, and I can't do that with a TTY. I'd like to know your perspective or concern about that kind of challenge in the workplace.

**David Coco:**
I have that challenge also in the workplace. The people that I work with have a cell phone to their ears. They walk up and down the halls. They use it in the car all the time. I made a personal decision not to become involved in projects that require the constant use of the phone like that. In some ways it hurt me because I work on projects that don't have a deadline in, like, 15 minutes. That hurts me in a way. In other ways, it took a lot of pressure off me. I know if I invested the time, money, and effort, I would be able to use the cell phone with a TTY. But it's just a personal decision that it's not worth it to me right now. I wish there was an easier way to do that, but I think I gained something from being released from the pressure.

**Lorie Shepard:**
I found that right now the closest I can get to that is the WyndTell pager. It works here in the hotel. I can take it pretty much anywhere. I learned some of the idiosyncrasies of that. It's not perfect, but it does allow me a certain amount of freedom and independence.

**Mike Ellis:**
Other questions? Yes, sir?

**Audience Member:**
I'm kind of like Brandi. I work in the service industry as a customer service agent. Since I have hearing, I'm on the phone all the time. At work I use a head set. It's great. I've got different hearing loss in both sides. When I use a headset, I get both sides, so I get most of the conversation. But the problem is when I'm at home with a standard telephone and one ear, I have discrimination problems in the phone, and I ask people to repeat. I was trying to find a head set in the stores that covered both sides. I can't find one. Lucent has the cordless phone which plugs in a headset, but they are all one sided. I'd like to know if you know where you can find double sided headsets. It would be a great help for me at home. I'm not ready to give up the phone yet as long as I do have some hearing.

**Mike Ellis:**
Comments?

**David Coco:**
There is something that I used a long time ago; you had to interface a phone to a speaker system, so that you can use regular headphones. I've done that at home before. You put
the telephone in front of a microphone and go through the speaker system. Using an amplifier that way worked well, depending on your speaker system. However, it is not cheap, unless you already have a stereo in place.

Mike Ellis:
Question? Yes, ma'am?

Audience Member:
Earlier we addressed the frustrations and misery we feel when we can't hear on the phone. Lorie mentioned how slow we have to type. But I would like to bring attention to something else. It's the quality time. People who talk to us on the TTY, on the e-mail, and know we are hearing-impaired, take the time to do it. That's quality. If somebody doesn't want to take the time to talk to me, good-bye. I don't want to hear from them.

The reason I mention this specifically is because my son is 21 years old and went to college. Just 2 days ago he e-mailed me from college and spent 30 minutes as he was typing with one finger. But the point is, I was in contact with him for 30 minutes. This quality time would not have been possible elsewhere. Sometimes we have to look at things from a different perspective. We can't help not having hearing. So we should rejoice in what we have like the relay system and all those things. How do you see that? Can we make our life easier if we look at it from a different side and see it as quality time? I'd like the panel to address that.

Mike Ellis:
Let's talk about quality.

Heidi Adams:
Yes, I think a lot of it is in perspective and attitude, which is what you are talking about. Yes, relay is wonderful. Someone yesterday in a meeting that I had, he said he learned that part of his philosophy was that if we walk in place, it's the same as failing; that we need to move onward. So, I think we do need to push to make it better.

Mike Ellis:
Yes?

Audience Member:
One morning I awoke and heard nothing. That was 30 years ago. There was no TTY. There was no captioning. There were no interpreters. There was nothing. My family lived 400 miles away. I lost touch with my family. My husband was in denial. He wouldn't take calls for me. The children were too young. I lost touch with all my friends that did not live within my neighborhood, with all my family. For ten years I could communicate with no one.

Then the TTY came, one of these big old things that was noisy and clumsy. Eventually, relay services became available, although only during business hours, and it was wonderful, believe me it was God sent. So I agree with people who say that relay is a great thing. But I also think that all of the complaining and the dissatisfaction is great, because that's the only way we will grow. You have to have dissatisfaction. If everybody sat back and said great, nothing would happen. So, I think what is happening here is really the greatest.

Mike Ellis:
We have five minutes and lots of questions. Tom?
Tom Davinroy:
Tom Davinroy here. It bothers me that the general population is not expected to know about relay services. I spend a lot of time asking people, “Do you know about relay service?” Because I use relay services, whether they are good or bad, I use it a great deal. I ask other people, “Do you know how to use it?” Then I get people talking to me as a third person, “ask him this, tell him that.” So the general population needs a great deal of education about relay services, the same as it needs about computer literacy. Thank you.

Lorie Shepard:
In a more perfect world, there would be no barriers. What I see as the biggest barrier that we face is economics. Because I believe that if we could publicize, if we could have ads, if we could have something during the Super Bowl to have Whoopi Goldberg call Marlee Matlin and say something profound.

People, even those of us who use it, don’t fully understand relay and how it works. I believe that education is the real key to being successful, not only in life, but also with the relay call.

Audience Member:
Thank you. My name is Mark. I have often heard people mention how they wish relay was more transparent or they had complaints about how relay in their state operated. I’d like to comment on how we as consumers can influence the current technology that we have. You know, if you don’t like the way relay in your state runs, keep a pad of paper next to your phone. When something happens that you don’t like, write it down. There’s one state that I visit once in awhile, and make a relay call in. I have to give my phone number to the CA. I hear nothing at all until the person on the other end of the line picks up. That makes me crazy! If I lived there, I’d write that down every time it happened. Then, I’d call relay CA and ask her to transfer my call to customer service and get the name of the account executive for that relay system, and find out how to contact them. Snail mail, e-mail, fax, TTY, whatever, and send him a list of these things that need to be changed. Then I would find out from probably the state commission on the deaf and hearing-impaired, who the members of the relay advisory board are, and find out if there is someone from SHHH or the late-deafened community on the board and contact that person with these issues. Okay. That will start the ball rolling with letting that relay provider know what changes in training really need to be made. Then contact the state Department of Public Utility Control (DPUC), or whoever works the contract when the contract time comes up, and tell them that these are the issues that you want changed. These are what you want in the new contract. Then find out when the contract is up. When you do, you get the information from the DPUC to find out who the vendors are that will be submitting their proposal for the contract. Find out which vendors will offer the things that you want. Then you can contact the DPUC and tell them that I want this person here.

Now, the more people who do that, the better your chances are of getting a good relay system. In my home state, we have who I believe is the best relay provider. When a contract came up for renewal two years ago, it was down to the low bidder. What we did was get a letter-writing campaign going with ALDA and SHHH and the state association of the deaf and the deaf/blind. The Connecticut DPUC ended up giving the contract, a 5-year contract, to the provider that we wanted rather than the low bidder. So we have got good services. I’m sure the low bidder saw that and they know in our area they will have to improve to be more competitive the next time the contract comes up. That’s something we all can do as consumers so we have better services. But if we sit there and say I wish it was more transparent, nothing will happen.
Mike Ellis:
Time is up and I'll give a few minutes to each panelist to have any parting shots. Then we will close for the day.

David Coco:
I would just like to follow up on what Mark said and challenge you people to become more involved with your local relay advisory committees. I think that we have a special obligation because we understand what good relay service can actually be like. Other people that use relay don't. So I think we have a special responsibility to help relay providers and the utility commissions to get past that hurdle to provide something that gives us what we need.

Linda Mazzola:
I think it's important that we have trained relay operators; relay operators that know how to type, they know how to spell, that can keep up with us.

Lorie Shepard:
A lot of times I'm told it sounds like I hate the relay service, and in fact, really the opposite is true. My goal is to see relay services become better and better, not only for the State of California, but for everyone.

Heidi Adams:
I really don't have any further comments. I think that both Mark and David said it, and said everything that needs to be said. You just need to exert your power as consumers.
The focus of this workshop is on wireless telecommunications such as pagers and cell phones. The format encourages your participation by asking questions and sharing information. I will be using WyndTell, an interactive two-way pager, as an example of a paging system because it happens to be the one I know the most about. I hope to demonstrate how to shop for equipment appropriate for you. But I also hope you will feel some excitement for what is possible in wireless telecommunications!

Until last November, those of us with serious hearing loss really had no way to communicate if we found ourselves stuck in a heavy snowstorm, out of gas on the freeway, or late for an appointment, going home, or picking up the kids. Also, many of us are working at jobs where we feel some restrictions because our colleagues are using voice mail and we are not. They might be in and out of their office but always in touch, and we are not.

I once had an employer tell me, “Judy, you are hard to reach when you travel.” To me, it came across as criticism. I wanted to argue about how difficult it is to find a pay phone with a TTY, or a pay phone with a shelf for a TTY if it happens to have one with me.

Now I don’t have those problems any more.

We all see drivers talking on a cell phone and some of us may feel envious of the convenience they enjoy.

Now I can sit on a plane while waiting for take off, pull out my WyndTell and send e-mail, faxes, text-to-voice and messages to TTY. I also get messages from e-mail, voice, and TTY. While doing so I become aware of the suit sitting next to me, watching me and he leans over and asks, “What are you doing?” and I say “I’m sending a fax to a customer,” and I look at his face and realize HE is jealous of ME!

With WyndTell I can send a fax or e-mail anywhere in the world, a message to any TTY in the USA, or a message to any voice phone. E-mail is included at no extra charge with the WyndTell service. It is also convenient in the other direction because there are people out there who can use whatever communication method happens to be convenient to reach me.

My parents are in their 80’s and their health is not good. I worry about them a lot and wondered if they would understand how they could contact me via pager. But they only have to know one toll-free voice number and can send a message to me any time without wondering where I am. Equally important, I can easily send messages to them. They just answer their ringing phone and hear my message spoken to them in a computer voice which can be repeated as often as they like.
How Does It Work?
WyndTell uses a network of wireless towers, providing service virtually anywhere in the U.S. This network is similar to cellular telephone networks, but it transmits using radio waves, and it carries only data or text; no voice.

Sending . . .
When you send a message 1, it travels to the nearest wireless tower 2. From that tower, your message is sent by traditional computer line to the Wynd Gateway 3. Here, the computers determine the type of message you sent, and the message is then sent out over the appropriate network to the recipient (the message arrives in seconds!) 4.

Receiving . . .
While your WyndTell is turned on, it constantly notifies the Wynd Gateway of your location. Then, when someone sends you a message 1, the message is first delivered to the Wynd Gateway 2. The Wynd Gateway then checks your location, and sends the message to the wireless tower nearest to you 3. The message then travels through the air and is delivered directly to your WyndTell in seconds 4.

WyndTell 950
(shown actual size)
Now, moving on to cell phones – these work very differently. Have any of you had experience with a cell phone? How do you use it? Do you like it?

**Audience Member:**
A cellular phone works well for me. I have an Ultratec 4425 TTY and I carry it with me when I travel. I use it with a Motorola cellular phone and you need to add a connection that is also used with a standard telephone RJ-11 connection. Motorola also offers that and I can set up the system in my motor home and use it for TTY conversations.

**Judy Viera:**
That's a good basis for comparison between a cell phone and paging technology. When you use a cell phone you are having a "live" conversation and when you are connected to the other party, you are paying for the whole time you are connected. Your cost will be determined by how far you are from the other party and how long you talk (using air time). By contrast, paging service is designed for text only and you prepare your message in advance. Then you press one key and your message is sent in a very brief burst of air time. Consequently, the service costs a lot less than cellular.

With paging service, there is generally a monthly service charge with a certain amount of e-mail messaging included free. There are usually two or more service plans so you can select the one that best meets your needs. Other services – such as sending to a TTY anywhere in the USA – are charged on a per-use basis with no long distance charges like on your phone bill.

**Audience Member:**
SkyTel uses the Motorola pager – don't they also offer one with a keyboard like WyndTell?

**Judy Viera:**
SkyTel does offer several different paging devices, including small thin ones that only show a phone number that you need to call and you have to go find a telephone in order to do that. Those are one-way numeric pagers. You know who to call but not what they want to tell you. At the other end of the spectrum you can send and receive text messages. They also have the Pagewriter 2000 that is a two-way paging device similar to WyndTell.

**Audience Member:**
What is the most cost-effective product for someone who only needs it for emergencies like you mentioned before?

**Judy Viera:**
I don't want to put myself in a position of telling you which one is best for you, but you might ask yourself first if you want one-way or two-way communication and that will separate the men from the boys. My personal preference is two-way because if I send a message to call for assistance I want to know it was received and that help is on the way. I want them to be able to communicate with me, too. Beyond that I would think about who I might want to communicate with and what methods are best for reaching them. TTY? Voice? Fax? E-mail? For me, there are people who have only a TTY so that is important to me. I also want text capability, not just numeric, so I can explain what my emergency is.

**Audience Member:**
What is the life expectancy of the battery of the cell phone? They only have standby of about 24 hours.
Judy Viera:
Good question. I know that cell phone batteries are also very expensive. I've seen them in catalogs. WyndTell, by contrast, only uses one or two AA batteries, depending on which model you choose. Also, it has a timer you can set to automatically turn the device on and off at the same time each day; turning it off while you sleep, for example, to extend the battery life. Battery life is also affected by how often the device vibrates to alert you to new messages.

Audience Member:
Returning to the subject of e-mail, what happens if someone sends me a message while the WyndTell is off during the night?

Judy Viera:
When you turn it on in the morning you will receive the message because the system knows your pager is off and will hold the message until you turn it back on. I'm glad you asked because this highlights a very important difference between cell phones and pagers. With cell phones you might be out of the signal area or cut off in the middle of a conversation and not realize it. You will not receive calls or be cut off in the middle of a conversation.

Audience Member:
I was in the emergency room at a hospital and tried to send a message but there was no signal. What would be the reason for that?

Judy Viera:
Sometimes hospitals have equipment that can present a problem and you have to go near a window or door to pickup the signal. You can tell from looking at the device whether you need to move a bit. It will also automatically continue trying to send your message until it connects.

Audience Member:
You are talking about a paging system – are there others different from WyndTell? Do you have to subscribe to a paging service? Also, do you have to be paged in order to talk on your cell phone? And what is the relationship of paging device to WyndTell?

Judy Viera:
Yes, there are other two-way paging services such as the one with Skytel that uses the Pagewriter 2000. Both paging and cellular services work like cable TV: you need the device and you need to subscribe to monthly service.

With the cell phone like this gentleman uses in his motorhome, he would add a connector and a TTY. Then he can pick up the cell phone and talk to anyone, including a hearing person via relay. Any direct connect TTY can be used this way. The Easy-Com Pro TTY from Ultratec is perfect for use with cell phones because it is direct connect only, is small, and has a very long battery life.

Now, with WyndTell, it has the ability to do voice-to-text and text-to-voice without requiring any other equipment.

Audience Member:
If I want to contact someone who has a cell phone, does he also have to have a pager so I can tell him to get on his cell phone?
Judy Viera:  
I am not sure how a person who is deaf with a cell phone would know about an incoming call.

Audience Member:  
To answer his question, it would be a total waste of capacity if you had to page someone you want to talk to via cell phone when you could just as easily send a complete text message to the pager and skip the cell phone entirely.

Audience Member:  
I have a question about e-mail: If you currently use an Internet Service Provider (ISP) like AOL or WorldNet on your computer, can you receive those messages with your pager?

Judy Viera:  
Some ISPs do have message-forwarding capabilities and can forward to WyndTell. AOL is one ISP that does not have message-forwarding. So that is determined by your e-mail provider rather than by WyndTell. But keep in mind that WyndTell can easily send messages to, or receive messages from, any e-mail address in the world, including AOL.

One other point, you want to stop and think about who you want to allow to contact you via cell phone or pager because you are paying for their contacts with you. At first, I thought I should be a walking ad for WyndTell and I put my pager address on my business cards. That was a big mistake! I don't want to have people using my pager for everyday e-mail. I'm very careful who has my pager address. I save it for my family and colleagues at work and temporarily for people I'm traveling to meet with.

Audience Member:  
Are you allowed to use cell phones and pagers while in flight?

Judy Viera:  
You want to crash?! You should turn off the equipment while in flight because you don't want to interfere with the pilot's radio communications. But while you're flying, you can easily prepare messages to be sent once you've landed.

Audience Member:  
You said that if you are temporarily out of touch with the pager signal, the network will hold your message and deliver it when you're connected again. But from my experience, WyndTell does that, but I have a regular AT&T alphanumeric pager and it doesn't hold messages it can't deliver. Also, my experience with WyndTell is that the battery will last for two or three weeks if you leave it on all the time and are not using the adapter.

Audience Member:  
I travel with so much technology! I think the airport(s) think I'm a walking time bomb! Is WyndTell affected when it goes through the security system at airports? Also, with my Motorola pager I get news, weather, sports, etc. Can that be done with WyndTell?

Judy Viera:  
First, going through airport security will not harm the WyndTell or affect its memory. About news services, some are free and others are available for a fee. They are not provided by Wynd itself but you can choose from among several such services via the Internet and just
put in the pager address to receive them. For example, I get U.S. and world news every day plus customized stock reports.

Audience Member:
I have heard that Wynd Communications is merging with another company and have also heard that "live conversations" will be offered. Can you comment?

Judy Viera:
Wynd has been in the wireless communications business for several years offering two other services, WyndMail and WyndPower, both designed for the mobile professional. The service uses the BellSouth Wireless Data network, previously owned by RAM Mobile Data. It is probably that change of ownership you were hearing about. With regard to "live conversations" you are probably thinking about features such as "TTY reply" where a message can be sent from WyndTell to any TTY and the recipient can send back a reply immediately without having to hangup and dial the 800 number to send a reply as a separate call.

Audience Member:
Can you use WyndTell for all your e-mail?

Judy Viera:
Yes.

Audience Member:
Can you send a message from the Internet to a WyndTell device?

Judy Viera:
Yes, very shortly you will be able to go to the Wynd website and send a message to a WyndTell customer.

Audience Member:
We live in Puerto Rico – is WyndTell service available there?

Judy Viera:
Not at the present time.

Audience Member:
Does Wynd plan to offer service in England?

Judy Viera:
I used to live there and would like nothing better than to go back and do that! BellSouth does have a network of some kind in Britain and I see that as a possibility in the future but not presently available.

Audience Member:
Is WyndTell available by leasing rather than purchase?

Judy Viera:
Yes, you can get it either way.
Audience Member:
I spend each winter in Freeport, Bahamas. Can I connect to Florida which is about 100 miles away?

Judy Viera:
Let me expand on your question. First, there are some places in the US itself that do not have coverage. The service is centered on metropolitan areas around the country and you will find no signal, for example, in the middle of the desert. As for the Bahamas, there is no coverage there. What is important is where the device is. It has to be in an area that gets the signal. So, for example, if you are in Florida with your WyndTell, you can send e-mail, faxes, and phone calls to the Bahamas because these go via the regular telephone network. Likewise, anyone in the Bahamas can use their computer or phone to send a message from the Bahamas to your pager in Florida.

Audience Member:
How far across the border with Mexico can you go and still get the signal?

Judy Viera:
I don’t know how far you can go, and it will depend on whether there are high hills in between you and the closest tower.

You start to sense what happens to the signal and can plan accordingly. There is also a simple way to check ahead of time when you’re about to travel. All you have to do is type in the zip code of your destination and you will immediately get back a message that indicates coverage.

Audience Member:
An important thing to understand is that cell phones would not be working right now in this room and your WyndTell is!

HANDOUTS:


Consumer Reports. (October, 1996). The price of cellular service, city by city.
This paper addresses selected issues related to *Telecommunications Relay Service* systems. The panel discussion is designed to help answer the question of: *Whose Relay Is It, Anyway?*

The panel consists of Linda Mazolla as Moderator, and three very strong advocates for relay service: Marylyn Howe, Tom Driscoll, and Judy Viera.

Marylyn Howe is one of the co-founders of the ALDA Boston chapter and past president of ALDA national. She is also the director for Massachusetts Assistive Technology Partnership, MATP Center, in Boston, Massachusetts.

Tom Driscoll, who works for Marylyn, is the coordinator of information and training at Massachusetts Assistive Institute of Technology. He is the former director of the Peer Assistive Technology Project, in the Cape Cod area.

Judy Viera lives in California and she has worked in the field of telecommunications for about 11 years in the United States and Europe. Before that she worked for UltraTech, and now with WyndTell. She collaborated with Marylyn and Tom to develop a proposal in response to a Request for Proposals (RFP) to set up and operate the relay service in Massachusetts.

This is the place to learn more about telecommunication relay service and how to develop successful new RFPs for relay service. These three people are strong advocates for high quality relay service standards.

**Marylyn Howe:**

The whole point of this paper is to show the reader how to develop a very strong consumer-driven RFP for telecommunications relay services in your state.

We will show how to do it as a professional, how to do it as a diplomat, and how to do it as an advocate. We will also show you how to learn to work cooperatively with those agencies within your state that can help you do it.

Our group in Massachusetts were recently asked to develop a new RFP for our state. I work for Children's Hospital in Boston and have been on previous RFP development teams. I felt that this time around we should maybe do things a little bit differently. This time I wanted to put together a group of strong consumer advocates to develop the RFP. I also created a second group of strong consumer advocates, different from the first group, to help us do the evaluation and the scoring.

This past summer, we organized a team to help us with the RFP. We did not want to restrict this team of strong consumer advocates to just Massachusetts. We wanted to find the cream of the crop from all over the country and have them join us in our team meetings through teleconferencing. We had people joining us from New York, California, Arkansas,
and Canada as well as Massachusetts through a series of teleconferences, which worked well.

We tried to pick consumer advocates who had expertise in areas such as proposal development, evaluation and scoring or some other section of the RFP. We assembled an excellent group. There were representatives from the speech-impaired community, the late-deafened community, the Deaf community, and the hard of hearing community. We included all groups who would be using relay service.

Since telephone relay services have been around in Massachusetts for the past 8 years, and in some states even longer than that, we reviewed some of the other RFPs that had already been developed. We used this process to do some "benchmarking" or some research analysis to show us which areas of communication relay service were the best in which states. The team then chose the best written policies and procedures sections from other states.

We looked at relay RFPs in Florida, California, Connecticut, Ohio, New Jersey, and other states. We picked which was the best in each area. That was the beginning of our benchmarking study. By the time we developed our own RFP, we had an idea of what we wanted. An RFP is a Request for Proposals. It is a document that gets sent out to bidders so they know what bid criteria they need to meet in order to be considered for selection.

This RFP is the document that actually will be the basis for the contract for the future relay service of Massachusetts. There will be some tweaking and changes to it but it’s really the basis of the contract. So that’s why we felt it needed to be strong and it needed to be good.

One of the things that was extremely important to us was to be credible to our community. In the RFP development process, we wanted to encourage as much feedback as we possibly could, even beyond the RFP development team. One way in which we collected this feedback was to ask relay service users about their likes and dislikes via a huge electronic distribution list we had. Feedback was brought to the team for review and discussion.

So we feel we have a very strong consumer-driven RFP. The process is not finished. Our state’s Department of Communications and Energy has two more weeks, I believe, to finalize it, to review it, and make changes to it if they want, before the RFP actually goes out to bidders.

Tom and Judy will talk about some of the specific technical and administrative specifications in developing the RFP and why they’re important.

**Tom Driscoll:**

First, a little background. There were tight time constraints in developing this RFP. There was a settlement agreement in March, 1998, which resulted in a timetable tacked on by an order of the state government. Everyone was locked in, with tight time schedules. Children's Hospital decided to bid on it, and won. Everybody understands it’s a hurry up job. We pulled it off in no time flat.

The poor bidders who win a bid to develop an RFP like this understand there is a very short lead time span – but it’s an equal playing field. They all have an equally short time to develop and write their RFP. I’m not confident the RFP is 100 percent done. We just went
to a public hearing, and I'm sure we will hear something about it. We have stuck with Mass General because we want to have an in-state relay. The RFP for the relay service must include plans to house it in a facility that is already in place. Our study of other RFPs indicated there is a negative factor in those bids which propose to set up a totally new facility because we then would have to consider the cost of building a facility, leasing space, rigging the facility, and even whether their bid is tied to interest rates for financing going up or down.

An RFP that requires strong clinical performance specifications, without the mechanism to assure service delivery based upon the specifications, are nothing more than a hook. They are not worth the paper they are written on if there's no enforcement and no accountability. Providers may groan and whine, a multi-million dollar corporation might groan and whine about fines, penalties, and accountability. However, the fact is there is nothing to worry about. If a provider delivers quality service, there's nothing to worry about. When we drive a car on the highway, we are not worried about a traffic fine because we follow the law. If we go to a store, we're not worried about getting arrested because we pay for our groceries. We see the world the same way. In developing a service and a product we hope the companies will see the same thing. If a company can prove something is unreasonable, and show it's unreasonable, it will be redrawn. There is a clause in the contracts to cover companies if an "Act of God" is involved.

The original RFP was a document that had very, very good specifications, but lacked enforcement clout. A good RFP should be able to prevent problems like:

- **Lack of adequate equipment.** There is no excuse for a large corporation not establishing budgets to obtain the proper equipment. There is no excuse for the corporations to lack resources. There is no excuse for not having enough lines set up, not having enough trunking capability, or switching capability. Barring natural disasters, or strikes, there is no excuse. Those exceptions are covered in the contract.

- **Personnel.** Staffing should be maintained at adequate levels. This is business. That's the way businesses are run.

- **Compensation.** Who wants to do a quality job for crappy pay? Certainly not an underpaid, overstressed relay operator. It's not a simple job. It's a very high-stress job. It's a very important job. A relay operator is doing for me – when I'm on a telephone – what this interpreter is doing right now, with a voice, actually. I'm seeing an echo.

- **Outreach.** There is an entire population out there that uses relay that is rarely thought of. They are the people on the other end of all the TTY calls. That group of people is the general public. We have industry, education facilities, medical organizations, government, legal fields, as well as family and friends who use relay. Every single relay call made has a hearing person on one end of it. I think there should be absolutely more outreach to the hearing population because most of the deaf population already knows about relay services. We have to be able to help the hearing population become more willing to use relay and not be so resistant to it.

- **Lack of adequate response.** The contractor's response to consumer complaints or consumer needs is the very essence of any successful business. Resolution to
problems, suggestion of alternatives, or at least an acknowledgment of the problem is critical. That's key. That's good business. That's the way the world goes around. Don't forget, the customer is always right.

We found that issues of enforcement and accountability played a major role in most of the better RFPs we reviewed. In Massachusetts, in 1998, we are using some of the same specifications we had before, the same quality of service standards, but we are trying to sew up the recognized loop holes of accountability and lack of enforcement.

Massachusetts had an excellent RFP which, unfortunately, had zero enforceability and what proved to be less than adequate accountability. It took a two-year fight to try to get some accountability. The state was basically hog-tied. There was no clear legislation that explained the procedure in the event of problems.

We endeavored to try something new with this RFP. We have consumers participating in a development team and the expertise of ten professionals who have been in the communication relay service industry for quite some time.

We understand that few telecommunication relay service RFPs have much input from consumers. Why not?

Whose relay is this anyway?

_Marylyn Howe:

Tom's question is a good one. You need to ask yourself if you live in a state that has a very poor quality relay service, what do you do about it?

Are there steps that you can take?

Do people know where they can go to complain about service and what needs to happen?

That is part of the problem. We are not educating our consumers about the complaint process well enough. Suppose we pick up the phone and make a relay call and the operator is typing terribly, the grammatical errors are terrible. Do we tolerate that or complain?

Often, even if we complain, we are ignored. Our complaint goes nowhere. Now we have this opportunity to develop an RFP on our own. We want to build everything we want from relay service into this RFP. We want to make sure they're the highest quality standards possible. As consumers, you need to know that you have a recourse, an avenue to file complaints if you're not happy with the relay service.

In Massachusetts, we filed a complaint with the Department of Communications and Energy (DCE) and the FCC. According to FCC regulations, both they and the DCE have 180 days to resolve the complaint. But it took longer than 180 days so they're in violation of the ADA.

Then the ball started rolling; the DCE started saying "We need to move this along." We got our state attorney general's office involved. The Department of Regulated Industries at the Attorney General's office was very, very helpful in representing us before the state agency, the DCE.
It was very time consuming, but it worked for us in the end because we had the opportunity to develop a whole new RFP.

Judy will speak next. She does not live in Massachusetts. She has lived all over the world. She has been involved in relay service development from the very beginning. I think Judy may have even started the concept of a relay service many years ago. So, Judy, we want you to tell us a little bit about your experience and how you felt that you fit into this process that we are working on together.

**Judy Viera:**

I am from California. Many years ago, the telephone company I worked for volunteered to provide relay services from 9:00 a.m. to 5:00 p.m. That was it. Then the California Association for the Deaf was able to get legislation passed that required the phone company to set up a relay service 24 hours a day, seven days a week under the jurisdiction of the Public Utilities Commission (PUC).

At that time the management of the relay was given to AT&T by default. There were no requests for proposals, no specifications, no rules, no standards. AT&T just had to wing it.

Nothing would have changed, except that the funding that provided the service went broke. The PUC set up a group of people to, quote, “fix the problem.”

I was there as a representative of the California Association of the Deaf. I was the only deaf person in that group. The others were from long distance phone companies and local companies in California.

With the help of lawyers from the Bay Area Center for the Deaf, they convinced the group that the quality of services was in our hands. The quality of service and the money go hand in hand. The specifications described how the services would be provided and, most importantly, that there had to be competition so that other companies would have an opportunity to provide proposals to run the relay service. That’s what happened. Sprint won the bid and served California very well for five years.

Then the competitions opened again and California chose a different approach to that RFP, a request for proposal. MCI won that time. They set up services and locations that really didn’t have access to an adequate supply of people to work as communication assistants. They bid at a price so low that they couldn’t even provide basic services. We went through many of the same difficulties that Massachusetts is going through. Now, California has two relay services and individual consumers can choose whichever one they want to use, whichever they prefer. You can choose your relay provider the way you do your long distance phone service, based on services or features.

California is the only state that provides consumers with choices.

I want to focus more in depth on how individuals who are late-deafened participate in the process.

California has administrative authority that involves the consumer. It’s different than most states. Most states, if they have anything, have advisory groups. They don’t have authority, but they advise. That’s different than California.
Related to the role of late-deafened people, I want to introduce Larry Littleton, the chairman of the California Relay Service and the advisory committee. They provide advice to the administration committee. Ron English is the late-deafened representative on that committee. Lori Shepherd, who is here also, is a member of the California Relay Service advisory committee. Late-deafened people are definitely involved. They have a role to play because there is a specific seat on the committee targeted for late-deafened people.

If your state has an advisory committee or an administrative committee, you should check to see if your interests are represented on that committee.

There is great diversity in the population of people who use the relay:

* People who are culturally deaf from the Deaf Community,
* people who are hard of hearing,
* people who have speech impairments, and
* people who are late-deafened.

All four of those groups have different interests and different needs and different priorities. Each group requires different representation at the state level. You should check and see how your state is set up.

I would also like to point out that deafened people played important roles in introducing some of the concepts that have been incorporated into resolving problems in relay situations that some of you face every day. Did you know that a late-deafened person introduced the idea of voice carry-over (VCO)? The VCO feature now available through telecommunication relay services came from a late-deafened person.

VCO allows you to speak to the hearing person through the relay. That service feature was not there two years ago. It came from the minds of late-deafened people. Also, I'd like to mention that ALDA always sends comments to the FCC, which has the ultimate authority for setting up the national standards for the relay services.

The California Association has been encouraging the FCC to give every individual choices in relay provision. This association also encourages the FCC to focus more on what we call "realtime relay." The goal would be to come as close as possible to the natural flow of communication between two parties. Currently, the communication flow often seems so slow as it is being transmitted between two persons. This is due to the fact that communications assistants (CA) cannot type or express what you are saying fast enough. That makes the conversation very awkward. This laborious, slow transmittal becomes an unpleasant experience for both people involved.

We're encouraging the use of better technology and better skilled communications assistants to improve the quality of services. So you, as late-deafened people, have a voice here in ALDA as well as back home within your own states.

We have found that in some states, consumers, whether they are culturally deaf or late-deafened, have no voice and no opportunity to participate in the development of the
relay system. We won't mention any states' names, but if you ask, we could tell you. It's a very, very sad situation for consumers in some states.

The states of Massachusetts and California are two places where consumers will never let go. Consumers will always be there in the front end explaining and asking for what they need.

I have had the opportunity to participate in the development of the Massachusetts RFP and it was a wonderful experience. We emphasize consumers. It's a very diverse group of people and they understand each other's needs. We're not trying to develop a system where they serve only one group but to serve all the groups.

Marylyn Howe:
Thank you, Judy. What we want to do next is to open this up to participants by asking what is it in the relay service that you would like to have that you don't yet have?

What is it about your relay service that really bugs you that you would like to get rid of?

Audience Member:
When I use the relay service, it seems like the communication assistant is in a hurry to get off the phone. Especially when I complete one call and I have another call to make. They hang up. They usually ask you if you want another call, to go ahead, or SK. But it's like they hang up immediately, already assuming I'm going to say SK. I'm saying "go ahead" and I'm waiting. There's nobody there. Then I have to dial again.

Judy Viera:
I'm curious to know what state you live in.

Audience Member:
Illinois.

Tom Driscoll:
I would suggest you check the regulations. I'm sure the way it's written the customer is allowed numerous calls. If the customer is allowed numerous calls, you have a complaint on your hand. As to whether you can file a complaint, I don't know.

If there are several other people with the same problem you have, then you have a voice. It's not a single complaint. I have seen the problem come and go in the state where we are.

Marylyn Howe:
One other thing I want to comment about is that there are ways we can take control of a situation and that would be to say to the operator right up front, "I plan to make multiple calls, so please do not hang up when I finish this call." That way the CA will be on guard. It alerts the CA to the probability that I'm going to call back and complain to the supervisor if she/he doesn't.

Audience Member:
I wonder, why do they have to tell you they're male or female. I mean, I don't really care whether an operator is male or female.
Judy Viera:  
I want the relay to be as invisible as possible and if I'm speaking to someone else and they hear a man's voice, they will know there's another party there. If I'm involved in a very intimate conversation with a man and he hears another man's voice, I think it's going to seem very awkward to him.

Audience Member:  
I never thought of that.

Judy Viera:  
That happened to me. I do try to help them by telling the person I am calling that I am going through a relay operator. If I'm talking to somebody that already how to use relay, I tell the operator.

Marilyn Howe:  
What are the other features you would like to see if a relay that we don't have?

Linda Mazolla:  
Let me think now. I know I have complained about this before. I recommend that we let the relay operator know before we make a phone call that you want to make numerous calls. Sometimes when I call and there is an answering machine, I forget to tell them please don't hang up. So they're typing all the words and then they hang up.

I call them back and ask, "Why did you hang up? I wanted to talk on the phone." That's frustrating to me because it took me maybe five minutes to get a relay operator and it was an important call I needed to make. I know, maybe part of it is my fault; perhaps I should explain to them before I make a phone call. But I feel like I want to make the phone call the easy way. Why should I need to plead with them to, "please do this, please don't do that."

Tom Driscoll:  
Having to take special steps is not right. In the Massachusetts 1995 RFP, it says the CA is going to be the last one to hang up; so you have the hearing person on one end and the TTY user on the other end. The relay operator is supposed to let them both hang up and then hang up last.

It might be an overstressed CA from Illinois hanging up; maybe they are understaffed.

Audience Member:  
I would like to follow up to the point brought up earlier about the relay operator, the CA, who was hanging up before the deaf consumer had the chance to make the next phone call.

I work with the Illinois Communication Access Corporation. We don't have a back-end connection. Illinois does not have that. We expect that all of them should be on-line so that when you're finished with your phone calls, you go ahead and hang up. You said the CA should be the last person to hang up. I wanted to clarify that to every one here in Illinois: if there is a complaint with the system, we have a very specific place where the individual can file a complaint. If anyone has a complaint in Illinois, feel free to come up to me and I will explain the system to you and provide more specifics about the system itself and the center.
Judy Viera:
I want to emphasize that the most immediate thing you can do is to ask for a supervisor right then. I know you have to dial again, but dial again and ask to speak to a supervisor.

There is a definite advantage to continuing with the same CA, because by the end of the first call they are accustomed to your needs and expectations. The second call may very well be related to the first call. All of that familiarity helps to improve the quality of the service on the second call. It makes no sense to have to call back and get another CA and go through your explanation of what you want and need. Start by getting the supervisor on the line.

Tom mentioned sanctions and penalties and the need to include stiff sanctions and penalties in the developing RFP. These are not just negative sanctions, they can also act as incentives for the relay service providers to take advantage of new technology to avoid incurring additional costs.

One of the improvements being made, I believe starting soon in Atlanta and New York, is dialing 711 to access relay. In New York, I believe Bell Atlantic will be changing so that 711 will be your relay service.

They need to set up and complete what’s called the AIN, advanced integrated network, or something like that. AIN is a one-step procedure which is all integrated and set up so they can do this all on one system. Why can't we all have access to a simplified system like that? Wouldn't that be neat?

But what are some of the other technologies that could be out there that we could provide incentives for the relay providers? Ideas?

Tom Driscoll:
It would make it easier for us to make a relay call, but more important, make it easier for someone who does not use a TTY to call you. They would not have to remember all those numbers, like 1-800-439-0183, and so forth. Next you have to tell the operator, "Okay, now call a second number, the party I want to contact is at 508-5544." Those strings of numbers discourage people from calling you or using relay services. We need a simplified system that will give the world telephone access to you, to me, to all of us.

Marylyn Howe:
Any other ideas what kind of things you'd like to see in a relay service?

Audience Member:
In California, we are hoping to have a relay service provided in Spanish, from Spanish to English language. There are many, many Spanish-speaking individuals who have deaf members in their families and they find they are unable to communicate through the relay service with their own families.

So that's a new service that we're hoping to get in California in the near future.

Audience Member:
I have the honor of being the late-deafened representative in the state of California. My seat on the committee was made possible by a lot of people working to reserve a seat for a
representative of the late-deafened community on the California Relay Service Advisory Committee.

There is now a late-deafened representative on the deaf and disabled communication programs administrative committee at the relay level. Prior to my appointment, there was not a late-deafened community representative. That gives you a perspective of where I come from.

My wish and dream is that one day people will see advertisements on television because, really, a lot of the success of a relay call is related to people knowing about the relay service. A lot of times consumers complain that the introduction that the relay service gives has a marketing flavor to it. People get a phone call and it will say, “California Relay Service, have you used relay before?”

The recipient is wondering if this is going to be someone trying to sell them communication services or other such products.

My feeling is if there was more exposure to the hearing communities through TV, radio, and newspapers directed to educate the hearing public about relay services, that it would make the relay service itself work more efficiently.

**Marilyn Howe:**
Excellent point.

**Tom Driscoll:**
Massachusetts is trying to put in multi-language relay translation. There are many individuals, although not as many as California, who have a much larger Spanish community, but there are many individuals in Massachusetts whose family’s native language is not English. Many can’t communicate with their peers, their families, employers or anyone.

We're trying to get the multi-language feature included in our RFP. It is not yet assured, but we hope to pull this off.

If there is a service out there they want, people have to hook into it to make it work.

The second part involves outreach and marketing. Marketing is what we would like to start using. Before, outreach sounded like somebody showing up in a room like this, passing out buttons and saying here we are. Marketing is more like showcasing a product, a service, and really getting word out to the masses through the media.

In New Jersey, we learned that their RFP included specifications for marketing the relay services. It wasn't a requirement, but it was a requirement with an option. Your bid went in the standard way, but while you're bidding, the RFP requires you tell them what your bid would be if you are going to throw in half a million bucks a year for public relations. I think for their state it was half a million dollars.

The company that was awarded the bid had that clause in there and now they have to have TV spots, signs on buses, outreach to the industry, hit the media. So people who don't normally use relay can see it, the goal is to eliminate the mystery and opposition out of relay services and encourages the public to use the service in order to gain access to TTY users.
We're trying to put that in our RFP now as options under "outreach." The first one is okay, tell us what you got. You have three options.

- Number 1: Are you willing to spend $300,000 a year on outreach?
- Number 2: Willing to spend $500,000 on outreach?
- Number 3: Tell us you love us, how much do you want to spend?

We want to give them as much room as they might need to make a competitive bid. We want to encourage them without restricting them, but we do have to get outreach for the hearing end. Because we all know about relay and most of the people out there who you call the first time say, "What's a relay?" They think they can switch an A/B switch or something, which shows that they have no clue what a relay is.

**Audience Member:**
I want to know, have any of the relay services figured out how to solve the problem that when you call someone and you get their answering service that they always type every single word on the answering machine message. Then they say leave a message after the beep and they say it's too late and they hang up and you have to redial. Has any system been found to make that work better?

**Judy Viera:**
One state, Wisconsin, I think. Either New York or Wisconsin, was the first to include in their RFP a requirement that bidders submit a message for electronically captioning recorded messages so that they can relay verbatim to the customer.

Some customers don't want to know what the full outgoing message is and only want a summary, and some do. Some states allow the operator to do a summary if you want them to. Personally, I want to hear everything I would hear if I heard.

There are other people who only want a summary.

Like you, I know I'm going to get an answering machine from time to time. If I want to know what the message is, I ask what the message is.

If I don't care what the outgoing message is, I just let it go. Then, when the beep sounds, I go in, and relay my voice message.

That way I have control and I have those choices. You do also.

**Tom Driscoll:**
Consumer control should be the predetermined factor. You're going to have a regulation somewhere in your RFP that says the operator must type everything. That's presents a conflict for the CA. It says the operator must type everything.

The operator gets to an answering machine and thinks, "I'm stuck, I have to type everything." But if the consumer is in control and says please do this, do that, the CA should be able to follow the consumer's orders without breaking the verbatim rule.
There's a battle every time we try to talk about that. It's like the age-old argument in deafness over whether to learn sign language or oral means of communication. Should it be translated, how well should it be translated, every word or most every word. I think it will be an ongoing fight. The bottom line is, the consumer should say, "Skip the message, I'm calling home, I know it's going to be my wife saying, 'Hello, I'm not here.' I want to leave a message, period."

Judy mentioned capturing a message. The CA would be able to take it right there on the spot. Hang up and redial back just about in time for you to leave a real long message. Another advantage of capturing messages is the ability to send the same information to several people without having to retype it all. Suppose a deaf person who is teaching a sign language course uses a TTY to telephone students in the class. If they're new students, they probably won't have a TTY. It snows, it rains. You now have to make multiple phone calls to let them know the class at 7:30 Wednesday night is rescheduled for next Wednesday at 3:30 p.m.

If the relay operator can receive an announcement where they can capture the voice and send it out to other persons, why can't they also capture my text one time and voice it out as many times as I tell them to? As long as I'm right there waiting, I'm still there on the call.

We're not sure how people are going to react, how relay companies are going to react. Our feeling is fair is fair: if you can capture a voice message, why can't you capture a text message? The consumer is off the line quicker, less money spent, state saves money, providers save money.

Consumers save sweat and fingers.

We will see how it works out.

Audience Member:
I have a question about the way different states handle the relay. I find a lot of people get confused by what's happening. They think they're being solicited or something. One of my friends suggested that operators might say, "This is Miss Greene, she's hearing impaired. She wants to communicate with you. Have you used the relay before?" Or something like that, so the person understands a little better what's going on.

Sometimes I tell the operator not to say anything. I will explain. I just say, "The operator is typing what you say and I'm reading what you tell me on a one-line computer screen." They seem to understand. Sometimes when the operator says it, they get all confused or hang up or something.

Judy Viera:
I think that whole introduction business is fraught with peril. Whether or not I want to take the time depends on whom I'm calling. But I try to take control of that, too. I will tell the CA, "I will explain this, let me start." Because I will explain it my own words it will be first person and I can explain it in a way that the other person will understand. I can say, "This is Judith." I just do not want to leave it up to the CA because if I do, I'm more likely to get the other person to talk to me in the third person. If I do the explaining from the beginning, then it's always between me and the other person.

But sometimes I don't feel like bothering.
Tom Driscoll:
Another point to make is the fact that many people who are CAs now may have come out of telemarketing fields. I know in certain states they have. They might have that certain bite to their voice for all I know. I don't know what it sounds like to talk to a marketer. It's been too many years. If somebody said a TTY user is on the line, you remember what your mother used to tell you: "Don't talk to strangers."

You don't know who the hell it is. You don't know if it's one of those scams that people talk about. People get put off.

Another factor is the word, "relay operator." It sounds much more functional on the telephone. You call and the operator says, "This is the operator speaking," you know you got the operator.

But if someone says, "This is a communication assistant speaking," we don't know what to think. Regular relay users all understand. But a first time person answering a telephone goes, "Huh? I don't need any assistance, what is this for? I didn't dial directory." They're put off, they don't know what's up.

The deaf-blind community in Massachusetts spoke up loud and clear two years ago and got CA changed back to OPA, operator. They also changed how they will communicate with relay operator number. This change in label is good for visual clarity, since the GA and CA look too much alike to deaf-blind TTY users. Operator also sounds more traditional to someone who has never used a relay service. An operator calls, you say okay. Somebody calls me long distance they're not going to hang up. A "communication assistant" can scare them.

Audience Member:
I'm a staff person at the relay program in California. We have been talking about these issues regarding operator introductions with our outreach subcommittee. We can't require the relay service providers to say specific words right now. It's not a part of the contract. But we may make requests later and we were thinking of incorporating the same thing by saying, "This is a relay operator" sounds better than a service. When you hear the word "Service," you automatically think they're trying to sell something.

Also it's important to acknowledge that late-deafened community is so much bigger than the culturally Deaf community. CRS was started for the deaf community. But now we have more late-deafened people using it than culturally Deaf persons. So you have different users of the relay service and these different users each have different preferences for ways in which they want it explained.

Many culturally Deaf persons would allow relay to explain it rather than to explain it themselves. Whereas, maybe a late-deafened person, would prefer to take control of the call and say how the explanation should be worded.

Marilyn Howe:
Okay. Do other people have any ideas of the types of technology or things that they would like to see in a relay service that they don't currently have? Tom?
Tom Driscoll:
I have a comment to make on this. We have seen comments about the communications assistants and the problems that are involved. I'd like everyone to remember that these are real people. It is, as we know, a very stressful job. So I make a point with every call that I make to thank them for their help.

If we remember that they are people trying to do a job for us, if we can stop complaining, but try putting ourselves in their position, we will get a lot further along.

Audience Member:
I remember last year when I went to the Miami convention, Ultratec had a videotape on a voice recognition program they were using with communication assistants that would boost up the words per minute. I brought that up to CRS Advisory Council and some of the criticism I got was a lot of people don't want the words going in faster across their screen.

I think that's fine for some people. But I'm thinking about people like myself; I'm used to working at a computer, I'm used to the words flying by me on a computer in a chat room as fast as you can type them in.

Would I like to have that option to have a faster CA? To have turbo code turned on? I know in California they just turned on turbo code. You need to dial a special number and you can have turbo code.

So that's starting to happen.

I'm wondering what happened with the communication assistant voice recognition program, why more investigation into fitting this into the relay service hasn't happened.

Tom Driscoll:
I will comment and ask Judy to also comment because her former job was with a company I was talking about. Right now all the operators would need to be trained. It's an intensive project to get them trained and to get the equipment trained to them. Each computer must be trained to their voice and they become trained to the console.

Judy Viera:
One thing I would like to see is access from the Web to whatever relay service providers we have a contract with, so we don't have to disconnect and connect to call a number. We should have Web page access to a chat room within the relay service which would enable us to chat with them "live" as they relay our call by voice. We should be able to watch everything on the screen just like they do. That's what I would prefer – not having to disconnect and then call relay if I'm already on the computer anyway.

Marylyn Howe:
I think one of my dreams is to have realtime relay using the CART reporters, the computer aided realtime translation. We don't currently have good speed capabilities with TTY. But this gal on my left who is doing the captioning is capable of typing in speeds up to 200, 250 words per minute. Which is the rate of speech.

But we have very slow machines, so we have to figure out how to change that. Maybe we can increase the rate by using computers instead of TTYs. I'm looking forward to the day when all TTYs get thrown out the door anyway.
**Tom Driscoll:**
Right now we do have the capability to send that many words over a line but we get to the same issue, training enough CART reporters to meet the demand.

Then they need experience, mentoring a while, getting their water wings wet. That means going to the courtroom, captioning events like this.

CART reporting is a highly, highly skilled process compared to a CA. I am not saying that a CA is not highly skilled, but CART reporting requires ten times more skill. You also need to get equipment for every CART reporter. Right now there are not enough people that could do it.

**Judy Viera:**
Tom just mentioned, California relay has turned on turbo code. In California we are able to send and receive much faster if our TTYs can keep up with that speed.

When you add something like fast text, or speech-to-text recognition, when you combine fast-tran with turbo code, you're getting pretty close to a "natural" flow of conversation.

**Marylyn Howe:**
One of the things I did want to say about this document, the RFP that we developed, even though it's very consumer-driven, we were hired by Bell Atlantic to write it. Bell Atlantic has the final say of what actually goes into it. So there are some of the teams' concepts and ideas that did get changed that we're not really responsible for, because this is an industry product. I just want you to keep that in mind. You can develop probably the best RFP in the world, but you're still going to have some restrictions placed on you by whoever it is that's hiring you to do it.
We are representing two organizations today: The Lexington School for the Deaf/Center for the Deaf and Gallaudet University. Gallaudet is the home of the Rehabilitation Engineering Research Center (RERC) on Universal Telecommunications Access. The Lexington School for the Deaf, in New York City is comprised of the School for the Deaf, Vocational Services Center, Mental Health Center, Hearing and Speech Center and Research Division. The Research Division is the home of the Rehabilitation Engineering Research Center (RERC) on Hearing Enhancement. RERC’s are funded by the National Institute on Disability and Rehabilitation Research (NIDRR), U.S. Dept. of Education. There are 15 RERC’s across the country, and each one focuses on a different area of disability research.

The RERC at Lexington Center focuses on hearing loss. Gallaudet’s RERC focuses on telecommunications access. Our goals are to develop and evaluate cost-effective technologies for people who are deaf and hard of hearing and to educate consumers about solutions that are already available.

Lexington’s grant was recently renewed and our goals for the next five years include collaboration with the League for the Hard of Hearing to train vocational rehabilitation counselors about pre-service and in-service programs on assistive technology. We will also work with Self Help for Hard of Hearing People (SHHH) to develop a national network of educated consumer leaders. We will hold training programs to teach consumer leaders about assistive technology and advocacy. We will sponsor a State of the Science Conference Series for hearing health care professionals like audiologists, doctors, and hearing aid manufacturers, to update them about assistive technology. We also plan to develop technical materials for hearing aid researchers, developers, and technicians. I encourage you to visit both Gallaudet and Lexington’s websites. They are full of information and links to other resources. Lexington has an assistive technology resource center in New York, which you are all welcome to visit.

CHILD-FRIENDLY AUDIOMETRIC TESTING USING ANIMAL SOUNDS

I am sure you have all had your hearing tested. You know how to respond when you hear the pure tone beeps. Testing children with pure tones is a challenge because the children are easily bored. Faye Erikson, research audiologist, wants to use real-life sounds, like animal noises. The problem is that real-life sounds are not pure tones. A pure tone is just one frequency, like 500 Hertz or 1,000 Hertz, but real sounds, like the vowel /a/ or a cat's "meow", have many frequency components. So when a person responds, we can't be sure if they heard the low frequency or the high frequency component. With digital signal processing techniques, we can determine the frequency components in any sound. We can adjust the sound to emphasize whatever frequencies we need. We will know exactly what children are hearing and will be better able to determine whether or not they have a hearing loss.
TINNITUS

Although people can describe what tinnitus sounds like or when it occurs, it is difficult to objectively measure its loudness or frequency characteristics. The Lexington RERC wants to find a way to objectively measure tinnitus in normal hearing people. It has been suggested that tinnitus in normal hearing individuals may be a warning sign of future hearing loss.

REMOTE CART (COMPUTER ASSISTED REALTIME TRANSCRIPTION) AND DIRECTIONAL MICROPHONES

If we were using Remote CART for this presentation, our CART reporter would not be in the same room with us. The reporter could be in another city listening through a speakerphone. See Figure 1.

The reporter would type what I am saying. The text would come back to us over a modem and onto a screen. We have tried this system with a deaf person who works for a bank in New York City. It worked fairly well, except for some computer software bugs and communication breakdowns. The CART reporter complained that she had difficulty hearing all the dialogue in the meeting. That was because we were using a speakerphone, which has poor microphone quality. We are developing a directional microphone to overcome this problem. You might actually have seen directional microphones, such as those used at big media events like football games, where you see reporters use boom microphones. Those are directional microphones. They have more than one microphone in them. They can block out the sound on the sides and zoom in on the sound directly in front of you. An omni-directional (regular microphone) will pick up sounds from all directions equally. (See Figure 2). It would, for example, pick up the sound of a plane flying and a man talking equally, which is not desirable. A directional microphone, (see Figure 3), with multiple microphones can emphasize sound from one direction.
ASR

Automatic Speech Recognition (ASR) enables computers to translate speech into text. Ultratec has begun a pilot project using ASR to help CA's (Communication Assistants) on the Telecommunications Relay Service (TRS). ASR systems are fairly reliable now, but the computer must be trained on a specific person's voice. We will investigate ASR in two conditions: 1) face-to-face communication, 2) telephone-like communication. We want to know: How effective is the communication? How do people feel about using this machine interface? Another application might be CART.

DIGITAL WIRELESS TELEPHONES

I would like to say a few words about the digital wireless (cellular) telephone interference problem. (Note 'wireless' and 'cellular' are synonyms. The industry now prefers the term 'wireless'). First of all, there is a difference between digital and analog wireless telephones. Most telephones out today are still analog, but the newer wireless phones are digital. Digital telephones can transmit data and voice. First problem: the digital wireless phones cause interference with hearing aids. So if you wear hearing aids, and you want to use a digital telephone or if somebody is sitting next to you using one, your hearing aid may pick up electromagnetic interference, like radio static. Behind-the-ear hearing aids pick up more interference than in-the-ear hearing aids. We are working with government organizations, the hearing aid industry, and the wireless telephone industry to solve this problem because it is denying accessibility to people with hearing aids.

Digital wireless phones are also not TTY compatible because they garble the TTY 'beeps'. Our goal is to create standards for reducing the electromagnetic interference between digital wireless phones and hearing aids and increase compatibility with TTYs. If you use a TTY and you want a wireless phone, you must purchase an analog phone. Unfortunately, you can't tell by looking at the phones which one is analog and which is wireless. You must ask. A direct connect TTY would work best. Audex has retrofitted some of the compact TTYs with a jack that allows you to plug directly into the cell phone; and Ultratec and Ameriphone are beginning to put audio jacks on some TTYs.

TELECOMMUNICATIONS FUTURE

We imagine that in the not-so-distant future, all forms of communication: voice, text, graphics, and video will fit into one portable hand-held unit. (See Figure 4).

PAGERS

The newest alphanumeric pagers can transmit TTY, e-mail, fax, and voice messages. For voice messaging, you type a text message and the paging company operators translate the message into speech and leave a speech message on somebody's answering machine. The costs for pagers are between $300 and $400, and about $30 a month usage fee.
Three companies in this market are WyndTell (800-549-9800), Skytel (800-759-6773), and Reachnet (888-RNET-008). Each offers different features.

**TEXT CHAT ON PC**

Two communication services are available for free on the internet: AOL Instant Messenger (www.aol.com) and ICQ (www.mirabilis.com). Both systems allow people to communicate using text, much like a TTY.

**VIDEO CHATS THROUGH THE INTERNET**

For video communication through the internet, you need: a computer (200 MHz or better), a camera (e.g. Panasonic Egg camera), a video card, an internet service provider (ISP), and the software, and NetMeeting – which is available for free from Microsoft’s website: www.microsoft.com. With this system, it is possible to communicate using video and text. For more information, please visit Gallaudet and Microsoft’s websites.

**CORDLESS TTYS**

Panasonic has come out with a cordless data adapter. It is designed to connect a cordless phone to a laptop computer. This adapter can also be connected to a TTY, for example the EZ Com from Ultratec.

For more information, visit our websites: Gallaudet RERC: www.tap.gallaudet.edu
Lexington RERC: www.hearingresearch.org

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Special thanks to Eune Hong for preparing this document.
Fifty years after surviving the Bataan Death March and a subsequent 42-month internment at slave labor in Japanese POW camps, a 70-year-old veteran was interviewed. He stated that he would not repeat his experiences for a million dollars, but recalled them as the most enriching, ennobling experience of his entire life.

As an adolescent, I would frequently attempt to educate my mother. One afternoon, I ended a tutorial with an important point I felt she should learn, “There’s something good in everything that happens.”

My mother, usually very calm and accepting, abruptly gave me a sharp, piercing look and asked, “What about your grandfather losing his sight? What’s so good about that?” My grandfather was a world-famous cardiologist who had written many books and was trying to write another, only he was going blind. I did not know the answer to her question, but I told her I would think about it. I still do not know the answer and I have been struggling with it for over thirty years.

Thirty-nine-year old Eric had also struggled with that question since losing his hearing four years ago. He arrived late for our initial meeting with what seemed like a prepared apology that he had overslept. It soon became clear that he had been, in his words, “burned by counseling before” and was therefore “iffy” about trying again, despite being quite depressed.

Soon after becoming deaf, Eric had sought counseling from the minister of his church. During their first meeting, the minister attempted to comfort Eric with essentially a theological version of my much earlier “tutorial” to my mother by proclaiming, “The Scripture says 'all things work unto good for those who love God'.”

Eric, however, was anything but comforted. He shot back, “Don’t tell me that ‘pain builds character’! You think my deafness is good? Sure – deafness might be a boon to a Garbo, a recluse, a hermit. Has deafness added anything to my character? Oh, yes – anger, hostility, frustration, embarrassment, to say nothing of the 24-hours-a-day problems of just trying to get by. Deafness sucks!” Eric then left and slammed the door behind him.

His anger was rekindled at the next church service several days later. He told me about not being able to “take it anymore” and leaving the service, muttering to himself, “Why should I say ‘Amen’? An almighty God wouldn’t inflict deafness on me like this!” He then headed to the nearest bar. From that moment on, Eric had dismissed God as nonexistent – dead.

When I told my mother that I’d think about her question, she politely informed me that I didn’t know what I was talking about. Since I didn’t have a vision loss myself, what right did I have to suggest that there may be benefits to my grandpa’s blindness? I had to admit, at least privately, that she had a valid point.
She still does. I do not have a hearing loss. So, for me to even wonder whether there may be benefits to it may be interpreted as arrogance at best, or, at worst, extreme disrespect. Neither is my intent.

Nor do I wish myself or anyone else to acquire a hearing loss in order to reap possible benefits. Woody Allen said it best. When asked about the spiritual benefits of accepting his own mortality, he replied, "I have nothing against death, I just don't want to be there when it happens." For myself, I often say that if pain builds character, there surely must be someone else who needs it more than me!

Nevertheless, it seems important to at least speculate about benefits to hearing loss even though no definitive answers may come forth. Specifically, I have witnessed many persons with acquired hearing losses go through a three-stage process:

1. **The coping stage.** One realizes and begins to actively confront the many subtle yet profound effects of hearing loss by adopting various coping strategies.

2. **The grieving stage.** One grieves and reluctantly accepts the limitations of hearing loss that one cannot change.

3. **The "out of lemons, make lemonade" stage.** One experiences a transformation from tolerating what one cannot change to finding ways to benefit by it.

Many say that benefits do not exist. As one deafened man wrote to me, "The only good news about hearing loss is an eventual cure." Or, as Eric put it, "Deafness sucks!" It is important to acknowledged that pain, rage and despair often, although not always, follow traumatic hearing loss. We must not "sugar-coat" them with positive affirmations. But, alongside the anger and distress, I also hear stories from people with acquired hearing loss that do not conform to descriptions of relatively superficial advantages to "coping with disability" nor to the "grieving process." Instead, I hear stories of transformation.

Crises have a way of not only crushing but also strengthening the human spirit. Although many clients request psychotherapy only to "feel better" as they struggle to cope with their hearing loss, there is another challenge; one that is more loosely defined and abstract. It is the challenge of answering the existential and often spiritual questions that their hearing loss has forced on them. In Eric's case, for example, his primary question was, "How could God inflict deafness on me?"

Although existential and spiritual questions must be continually asked and answered, they typically have no clear answer. However, to respond with neatly packaged answers or affirmations, as Eric's minister did, is inadequate, at best, and insulting, at worst. Instead, there are "pockets of gold" to be found in the eternal struggle to answer unanswerable questions. As psychiatrist Carl Jung stated, "When the unstoppable bullet hits the impenetrable wall, we find the religious experience. It is precisely here that one will grow."

Let us struggle to answer the question of what existential and spiritual benefits there are from traumatic hearing loss – knowing full well that the question is fundamentally unanswerable.
Psychiatrist, Victor Frankl, was a prisoner at Auschwitz during the Holocaust. There he also struggled with how to find benefits from loss:

It had been a bad day. We lay in our earthen huts – in a very low mood. Very little was said and every word sounded irritable. Then, to make matters even worse, the lights went out. Tempers reached their lowest ebb. But our senior block warden was a wise man. He improvised a talk about the many comrades who had died in the last few days, either of sickness or of suicide. But he also mentioned what may have been the real reason for their deaths: giving up hope. He maintained that there should be some way of preventing possible future victims from reaching this extreme state. And it was to me that the warden pointed to give this advice.

God knows, I was not in the mood to give psychological explanations or to preach any sermons. I was cold and hungry, irritable and tired; but, I had to make the effort and use this unique opportunity. Encouragement was now more necessary than ever.

I spoke of the many opportunities of giving life a meaning. I told my comrades that human life, under any circumstances, never ceases to have a meaning, and that this infinite meaning of life includes suffering. I asked the poor creatures who listened to me attentively in the darkness of the hut to keep their courage in the certainty that the hopelessness of our struggle did not detract from its dignity and its meaning. I said that someone looks down on each of us in difficult hours – a friend, a wife, somebody alive or dead, or a God.

The purpose of my words was to find a full meaning in our life, then and there, in that hut and in that practically hopeless situation. I saw that my efforts had been successful. When the electric bulb flared up again, I saw the miserable figures of my friends limping toward me to thank me with tears in their eyes.

Frankl came to believe that a person’s main concern is not to gain pleasure or to avoid pain but rather to find a meaning or purpose in one’s life. As he put it, “We can still wrest meaning from life by giving testimony to the most human of all human capacities: the ability to turn suffering into a human triumph.”

We do not “search” for meaning in the sense of hoping to find it. Instead, we actively make decisions about what meaning(s) to attribute to certain events: whether to perceive them as good/bad, important/unimportant, half-empty/half-full, opportunity/calamity, etc. Through our internal, self-talk, cognitive processes, we create, or construct, a meaning(s) for an event(s) which then determines how we feel and then what we do.

Unable to end the Holocaust, Frankl actively chose to construct a personal meaning to it: namely, he came to realize that any circumstance – including the Holocaust – can offer a purpose. His particular construction of meaning made him feel more hopeful and contributed to his psychological and spiritual growth, alongside the horrific trauma that he endured. His thoughts and feelings then spurred him to write his seminal book, *Man’s Search for Meaning*, and to become a renowned psychiatrist.
Hearing loss too, may offer an opportunity to create meaning. Again, to quote Carl Jung, “One does not become enlightened by imagining figures of light, but by making the darkness conscious.” By consciously exploring the “dark” aspects of hearing loss, fear, anger, depression, anxiety, one can achieve a level of psychological growth that transcends the “acceptance” stage of the grieving process. This odyssey catalyzes a person to construct deeper layers of meaning for one’s life.

For example, one middle-aged man with acquired deafness wrote me the following note, “Life holds many mysteries that defy answers. But we must not use these unanswerable questions as a negative about which to grieve. We can only move forward, positively, doing the best we can in life.”

This man explained many world-wide tragedies, alongside his own, as mysteries for which there are no answers. They had become part of his life that he was obliged to accept. His thoughts, or constructions of meaning, enabled him to feel humble and resigned. He then behaved in more purposeful ways: namely, to focus on what he could change, or as he put it “to move forward.”

Many others perceive their hearing loss as giving them a new and worthwhile direction for their lives. Some strive to correct various forms of societal oppression. They become “freedom fighters” against the wrongs of society that have been perpetrated on Deaf people. One deafened man, for example, interpreted his loss as offering him a new life mission. He took it upon himself to scrutinize and help reform the hearing aid industry. The more he experienced frustration and anguish, the more he increased his efforts to improve the lives of other hearing aid users.

**INTEGRATING DUALITY**

The following stories will hopefully highlight this rather abstract concept. One is from a woman who had become deaf while in her late 30’s:

> People used to say that everything I touched turned to gold. Everything came easy for me as a child; sports, grades, dates. As an adult, I graduated college, fell into a job as an editor and lived a fantasy kind of existence. But then I lost some of my hearing and soon I became deaf. For the first time, life became difficult. There were many things I couldn’t do no matter how much I tried. Painful as it was, and still is, I can honestly tell you that I have grown more in the last year than in the first 35 years of my life. I now appreciate what I have. I take the time to acknowledge how hard I have worked to be included at work and I like myself more. Sort of funny isn’t it, how it happened?

The addition of difficulty to her life helped her cherish the easy parts more and re-examine what was truly important. That easy-difficult duality added more contrast and texture to her experience of herself and her world. Oncologist Bernie Siegel has written about patients who were confronted with an existential duality – who, in his words, “have sort of died to stay alive.” He explained this as follows:

> I’m talking about your becoming who you didn’t want to be, because of pressure from parents or other authority figures – you become the doctor, the teacher, the plumber, the housewife, even if the work and role are meaningless to you. And then one day you are told you have a year to live. For some of you, learning that you are mortal finally gives you permission to live your life.

We are all affected by myriad dualities – the Yin and the Yang. Typically, we welcome one pole of the duality while we reject or fail to acknowledge the other pole: what Carl Jung called, “the
shadow." This is the disowned part of us which is the repository for those memories, thoughts, feelings, etc. that cause us distress. Nevertheless, as the previous stories illustrate, there are important psychological benefits to integrating one's shadow.

Integrating our shadow, however, does not mean succumbing to it. Bernie Siegel, for example, would never recommend that his patients resign themselves to more cancer. Our choice need not be either putting the pains of loss completely out of our consciousness or making it invariably present as our exclusive focus. Instead, we learn to place that pain of loss not in the center of our visual field where it would forever cast a perversively ominous cloud, but slightly off to the side where we can keep an eye on it while enjoying other areas of our lives.

By integrating our shadow in this way, we find the "pockets of gold" that are contained within it. This odyssey can in fact, give perspective and energy to our lives. To quote poet William Blake, "We should go to heaven for form and to hell for energy – and marry the two. When we can face our inner heaven and our inner hell, this is the highest form of creativity." Indeed, it may be that the tension within this duality is what fuels the work of many creative geniuses such as Pablo Picasso, Buster Keaton, Friedrich Nietzsche.

Heaven and hell, happiness and misery exists by virtue of its contrast to the other. They are dialectics. As a popular example, where would Luke Skywalker be without Darth Vader?

**CONNECTIONS TO CHERISHED MENTORS**

A woman named Carol told the following story:

About 30 years ago, when I had just turned 21, I was driving around with a bunch of friends. We were stopped at an intersection when a drunk driver hit us head-on. The next thing I knew, I woke up in a hospital, having been in a coma for several days. I found out later that all my friends in the car had been killed instantly. I very clearly remember, as if it were yesterday, lying there watching people's mouths move but being unable to hear their words. My hearing was completely gone!

For several long months, I lay in traction, hooked up to a bunch of machines with many tubes coming out of my body – trapped in a suddenly silent world. To say that losing all my hearing was traumatic is a gross understatement. But I eventually got back on my feet again. My dad always used to say, "You gotta get up a third time after they've pushed you down twice."

I had to take a year's leave of absence from college to recuperate. I was living at home with my parents, going to physical rehab and a host of doctors. I remember when it first really hit on a deep, visceral level that I was deaf and that I was going to be deaf forever. It was the middle of the night, about a year after I left the hospital. A terrible nightmare about suffocating in a plastic bag woke me up. My heart was pounding and my whole body was covered with sweat. Without any hesitation, I immediately went straight to my parents' room, like I was a little girl again.

For a minute I stopped in my tracks and stood there noticing how soundly they were sleeping and how very peaceful they looked. But there was no question in my mind that they would want me to disturb all of that. So, I shook them out of their sound, peaceful sleep and told them about my nightmare. We all knew what it meant.
My mother held me; I felt her body spasm and we both began to cry. She began to stroke my hair. My dad was sitting up in bed with one hand on my mom's shoulder and the other one on mine. He was crying, too. I felt real close to both of them that night. It was the first time that we really allowed ourselves to openly feel and express with each other the pain and tragedy of what had happened. None of us got any more sleep that night.

As the sun rose, my dad suggested we take a walk. I walked between my parents - hand-in-hand - just like I used to do as a kid, along the same paths in the woods that we had walked so many times before. The sun came up over the trees, through the mist, exposing the splendor of the colors of the woods. Although I guess it may sound corny to you, it was an epiphany for me.

We were quiet for a long time. My dad was the first one to break the silence. As we sat down on a triangularly-arranged group of rocks, he said very gently and lovingly, "You know, Pumpkin (his pet name for me), you'll get through this. You're going to have a full, happy and very successful life - but not without some blood, sweat and tears. You never have to shut us out from any of that."

We all began to cry again and we sat there for a very long time. The mist was gone and the sun by this time radiated through the trees. I think that that moment was the closest I've ever felt to my mom and dad. It was then I knew that everything would be okay.

Now, back to Eric, none of these benefits seemed relevant to Eric when I met first him. He judged his life as having "enough" meaning prior to his hearing loss. He had easily accepted the duality of "the ups and the downs." He had also enjoyed "hanging out" with people both similar and dissimilar to himself. Eric wanted none of that "silver lining bullshit" that he had gotten from his minister and was not about to give it to him.

Our task was to address and change how his life was falling apart. He had emotionally withdrawn from his wife and family. His work performance as a mail carrier was slipping. Socially, he used to hang out with his buddies, usually to shoot darts, his favorite hobby. He had even won several state competitions before becoming deaf. But his life was now melancholy. He spent his time at home by himself, often in front of a TV, with beer in hand.

For the next several months, we discussed various psychological effects of his hearing loss as well as what coping strategies he could use. He also allowed himself to grieve about those inevitable, disabling effects that he could not change. Gradually he became less depressed.

One day he walked in and proudly announced that he just won a local dart competition after practicing for "only a day!" His relationships had also improved. For example, he was looking forward to spending Father's Day with his family. Maybe he would invite some friends to join the party. And work was going better. Eric was clearly "getting back to his old self."

At the beginning of one meeting, I asked Eric what else he would like to work on. He thought for a moment and agreed that he indeed was much less depressed. But then, after thinking some more, he added, "I still feel that something's missing: a kind of emptiness, a void, that I don't remember feeling before I became deaf."

"You mean since you slammed the door on God?" I asked.
Although my question seemed to “come from left field,” it felt quite relevant. It was a question that would have once been uncharacteristic of me to ask. I recall feeling great relief several years ago when I finally became comfortable with spirituality. Immediately afterwards, clients began to discuss it with me during our meetings. Clearly, something else was going on.

Without missing a beat, Eric nodded his head. Prior to his hearing loss, his spiritual beliefs – the foundation of his life – did not account for undeserved suffering. Bad things could not happen to good people. He did not find solace in biblical stories, such as Job, which would have justified and even deified his suffering. Instead, Eric deemed God as having committed the ultimate sin against him. By slamming the door on his minister, he had “slammed the door” on God. He had sentenced God to death.

Eric was not alone with his spiritual outrage. Such befuddled betrayal is a common experience for a religious or spiritual person who has learned about – or experienced – any kind of traumatic loss. Throughout our history, humankind has wrestled with whether to hold God accountable for what has gone wrong in a world which presumably has been under divine control.

But like many others, Eric was left with what author Karen Armstrong called, “our culture’s God-hole”: our rejection and abandonment of God, leaving one with a spiritual void, an emptiness, a deadness. While negating God provided Eric with clear answers to all the “why” questions, it left a hole that could not be filled by family rituals nor by winning dart competitions.

The deadness and void that remained was not due to depression. As Eric so poignantly put it, “I realize that by killing God, I had killed part of myself.” He felt cut off not only from the church community but from a divine presence, one that had helped him never to feel alone. He remained a spiritual amputee.

“Maybe your deafness has prepared you for a different level of discussion with God?” I offered.

Eric was one-step ahead of me. He had already telephoned his minister to make an appointment. He was now ready to continue the conversation that was interrupted 5 years ago. As it turned out, his minister had been hoping for this opportunity, lamenting his much earlier “error in timing.” There would be no more simple answers to complex questions.

Several weeks later, Eric gave me a vivid account of their meeting. The minister offered no platitudes. Instead, he invited Eric to wrestle with God, much like many others had done before him. He was invited to vent his rage at God and demand an explanation. And when he could find none, the minister only offered his sincere condolences. “If only there were clear answers,” the minister would repeatedly say. In this manner, he validated Eric’s loss of an omnipotent, omniscient, benevolent God that would always make sure that nothing bad would happen. That God had died.

Eric was helped not to simply re-capture what he had lost – to return to his pre-deafness level of spiritual development – but to evolve in his spirituality. He continued a long tradition throughout humankind of coming to terms with so-called “unfair” acts in the world. Now, his evolving conception of God had to account for the duality of fair and unfair. Soon he began to resume attending church services regularly, but experienced the teachings much differently than he had before.

As Eric learned to tolerate, and then appreciate, the dualities inherent in his God, he also learned the same lessons with respect to himself. They were parallel processes; his God had a shadow and so did Eric. His own “shadow” contained his distress from his deafness as well as other “smelly, wet, dirty dogs.” Like King Faust, Eric allowed himself to fully experience and “embrace” his
shadow. By doing this, he not only grieved and learned to manage his shadow, but also “used it” to find those deeper levels of life's richness and texture that one only experiences while simultaneously holding life's agony and ecstasy in the soul.

For example, in his own words:

My wife thought that I had gone off my rocker the other day at the art museum. But it was something I could not explain at first. I usually don't cry, certainly not by simply looking at a painting. But there I was — staring at a beautiful landscape with vivid oranges, reds and blue sky. I burst into tears! Before, when my life wasn't so bloody difficult, I would never have appreciated such a beautiful painting!

His life now had deeper levels of meaning. The quality of his connections with others also changed. He proudly reported that he had joined town meetings to advocate for disabled persons' rights. His interest in dart competitions lessened (although he continued to win tournaments) in favor of “more intimate discussions with friends.”

There is a Buddhist saying that when the student is ready, the teacher will come. Eric's hearing loss had become his teacher.

As Eric was leaving my office one day, he remarked, “You know, Mike, I was a hell-of-a-lot happier thinking that life was fair before I became deaf, but I'm a lot wiser now.”

His off-handed remark echoed a profound truth: that every human experience can be expressed in terms of a paradox. In this case, less-happy but more-wise. Triumph and recovery do not mean living happily ever after. Nor do they mean a guarantee of no more suffering. Instead, as this chapter has illustrated, finding the “pockets of gold” can be a way to come to terms with this profound duality, to integrate it and hold it dearly in one's consciousness.

Before Eric left, I instinctively asked him, “If you could, would you trade wisdom for happiness?”

His answer was quick and to the point, “To be honest with you — yeah, sure I would. But I can't go backwards in time. So I'll have to take wisdom.”

Like the veteran from the POW camp, Eric would not have wished for his traumatic hearing loss for “a million dollars.” But it had become the most enriching, ennobling experience of his entire life.
LIFE AFTER COCHLEAR IMPLANT
Sharaine J. Rawlinson

I became deaf at the age of 14½ when I contracted spinal meningitis. I was a bright student, having completed 8th and 9th grades in the school year 1973-1974. My plan was to finish grades 10 and 11 the next year and then graduate in 1976 at age 16. Instead, my life took a very unexpected detour. I went to the hospital the same day I was to start my sophomore year of high school.

In the hospital, the meningitis put me into a coma for five days, running a fever of 105 degrees. I was paralyzed briefly, and the doctors thought I would not live. They told my parents that I might experience brain damage and be deaf and blind if I survived. Instead, I simply became deaf... totally. I went from perfect hearing to no hearing at all overnight.

Over the years, the one thing I missed the most was music. People who are born deaf often do not know what music is; they have no appreciation for it because they cannot hear it. People like me, however, who have lost their hearing post-lingually know exactly what they are missing. Music, for me, was my motivator for getting a cochlear implant.

Keep in mind, however, that my career has been all about advocating for and delivering quality services to deaf and hard of hearing people. I attended the National Technical Institute for the Deaf in Rochester, New York where I earned a Bachelors of Science in Social Work degree. While there, I learned American Sign Language as my second language. Over the years, I have taught independent living skills, job readiness skills, done job placement and clinical social work. I even had the opportunity to be the chief author of legislation in Missouri which established culturally and linguistically appropriate mental health services to individuals who are deaf or hard of hearing. At the time I considered getting my cochlear implant in Minnesota, I was Executive Director of the Minnesota Foundation for Better Hearing and Speech.

While I attended the University of Kansas School of Social Welfare for graduate school, I entertained the idea of a cochlear implant. Screened at the Midwest Ear Institute in Kansas City, Missouri, I was found to be a prime candidate for a cochlear implant. At that time, research was being done on the single channel 3M device. Even though I was approved for implantation, I was not ready to go ahead with the operation. I put it off because I wanted to finish school first. It was my belief that if the surgery was successful, I would be much more likely to spend my days listening than doing my homework and earning my masters degree.

Also, my marriage was founded on the premise of a deaf woman and a hearing man. I was uncertain as to whether or not my marriage could withstand the almost certain changes which would have resulted in the event that the surgery was successful. My husband and I were both concerned about facial paralysis. The auditory and facial nerves are situated in very close proximity to one another. One of the greatest risks a patient faces is the possibility of accidental facial paralysis resulting from an errant scalpel.

Finally, there were the political ramifications – my career being in Deafness, a field which does not endorse cochlear implants in children and tends to scorn pre-lingually deaf adults who opt for implantation – there were questions as to whether or not I would be damaging my career by getting an implant. As someone who was born hearing and became deaf later, I was always labeled a "deaf
person with a hearing mind". Even though I became fluent in ASL, and worked hard with and for deaf people, I was never considered Deaf. The "Big D" Deaf person is someone who is a native user of ASL, usually referring to someone who has attended state residential schools for the deaf, is totally submerged in Deaf Culture, and dismisses any need for sound. In fact, members of the Deaf Community do not consider themselves disabled; they state unequivocally that they are "just deaf." In 1985, when I first considered a cochlear implant, I was not ready emotionally, socially, or psychologically to take on the probable changes. Thus, I declined the surgery.

Twelve years later, I met cochlear implant users, successful users, both children and adults. Again, my curiosity was piqued. This time, however, I wanted to have the surgery done at Mayo Clinic in Rochester, Minnesota. Having divorced four years prior, the impact that implantation would have on my marriage was no longer an issue. At the same time, I was also blessed with the friends and family members who supported my decision, regardless of whether or not I had the implant.

My doctor, Dr. George Facer, and my audiologist, Ann Peterson, carried out extensive evaluations of my health and my cochlea in order to determine if I was still a suitable candidate for an implant. The entire evaluation took several weeks, in addition to the arguing I had to do with my health insurance company to approve the procedure. Ultimately, I was approved for implantation, and was selected to participate in the clinical trials by the US Food and Drug Administration on Cochlear Corporation’s newest model, the CI-24M. Rather than 22 electrodes in the Nucleus 22 model, the CI-24M has two wires, one with two electrodes for grounding and a second major wire with 22 electrodes which were threaded through my cochlea.

Due to cochlear calcification, people who have had spinal meningitis are frequently not able to have cochlear implants. In these events, implantation is impossible. In my case, certainly another rarity, my cochleae were clear, exhibiting no calcification whatsoever.

When I was switched on, the ability to hear sound was at once exciting and disappointing. The miracle, of course, was I did hear something! It was exciting in that I felt released from silence, as if physically pressure had been reduced on my being. It was disappointing because the sound I heard was not the same as what I remembered. Was I experiencing “euphoric recall” or was my hearing different than it had been? Likely, the answer is a combination of both. After 23 years of total silence, my brain would have to re-acclimate to sound and create new pathways by which to process and comprehend what was being said. Since my tolerance for sound was initially minimal, my audiologist had to set the threshold and ceiling of sounds being allowed in at low levels. Over time, she gradually enlarged the parameters for sounds to enter, and with practice I began to understand sounds and identify them.

After Ann, my audiologist, turned my implant on, she showed me around the clinic, indicating the sounds around me – water in a water fountain, elevator bells, footsteps, and so forth. I did not think that I would need this re-orientation. While I maintained low expectations of my implant, I had not banked on being unable to identify sounds again. I sort of figured if I heard environmental sounds, I would automatically know what they were. I was wrong!

Later, I would go out to lunch in a restaurant and find myself overwhelmed by the noise. I could not believe the loudness of the environment, the clatter of dishes and silverware, the crashing of glasses accidentally dropped, people talking around me seemingly oblivious to other conversations. How could they hear each other when everything was so loud?

After lunch I asked Ann to allow me to try and use the telephone. She was quite hesitant, but acquiesced when I said I just wanted to hear it ring and then would put it on TTY to converse with
the person at the other end. I dialed my office at the Midwest Center for Postsecondary Outreach in Saint Paul and heard the phone ring a couple of times, then there was a voice. I had no idea what Patty, my assistant, said but I heard her voice. I said, "Patty, I hear you voice! I have no idea what you are saying, though. Please put it on TTY." Just the ability to know if there was a dialtone and ring or busy signal gave a tremendous boost to my independence.

Hearing again has proven to be yet another challenge in my life. I expected some people to be supportive and others not. There proved to be occasions when I thought someone would be supportive, but they weren't. Conversely, there were people I expected to get criticism from who, instead, were supportive. Eventually I gave up trying to predict people's reactions. My attitude became, "This is my life and my body. The decision is mine and none of any one else's business." Overall, however, I have been pleased by the amount of support and encouragement my family, friends, and colleagues have given me.

Emotionally, the impact of my regaining some hearing has been far greater on my family and friends than me, to date. I think because it is happening to me, my body's defense mechanisms kicked in, just like when I became deaf. It is too much to comprehend at once; it's been a year and a half and I'm only now starting to feel the impact. In contrast, my family and friends have been moved to tears upon learning I had regained some hearing.

Over time, I have managed to build up to the ability to hear and comprehend again with some significant success. Take the telephone, for example. I have great success with people who are patient, speak and enunciate clearly and slowly. It is difficult, however, when the person I'm conversing with is soft spoken, talks fast, or has an accent. I've had to learn what I need, then assert myself and ask people to speak clearer, sometimes louder, and definitely slower so that I can pick up the various sounds and communicate effectively.

Early on, listening to music was frustrating and nearly impossible. Over time, with the enhanced parameters of my threshold and ceiling levels, I've re-learned how to hear music. Sound once splattered and splintered, now resembles the music I once knew. The sound of pianos, guitars, and other instruments gives me pleasure beyond description. To hear songs again and follow along with the words which are often enclosed with the music has reopened a world that I longed for.

This does not mean I hear perfectly, like a normal hearing person. I function like a hard of hearing person when I have the implant connected. When I turn it off, the battery dies, or I take the headset off, I am right back where I was before the implantation. Still, the wonderful progress has had its downsides. I'm constantly expecting myself to hear perfectly. And, I do so well that some people have wrongly assumed I am now hearing. It was, as I expected, easier in some ways to be just deaf. There was no need to explain, "I can hear this, but not this. I need you to speak up." I simply had to say, "I am deaf. I hear nothing. Talk slowly so I can read your lips."

Since the National Association of the Deaf has taken a formal position against cochlear implants for children, I am often asked if I endorse childhood implantation. To this I reply, "Yes, in some cases children will benefit from a cochlear implant. In others, I would not be supportive of such action." I believe that parents have the obligation and the right to raise their children. It is the professionals' responsibilities to make sure that parents have all of the information, not just parts of it. We must inform parents about sign language, educational options, cued speech, cochlear implants, hearing aids, and other assistive listening devices. To withhold information on one or any of these options is to carry out a breach of professional ethics, in my opinion.
Finally, I fully recognize that my experience with my cochlear implant does not mirror those of all implantees. There are those who have had marvelous success for a time, only to have the implant fail. Still others have had to give up their implant because when it was switched on, the electrodes stimulated their facial nerve and caused facial twitching that could have led to permanent facial damage. I do not believe that cochlear implants are for everyone. Anyone considering an implant must consider their motivations for doing so, the emotional, psychological, and social factors involved, in addition to the physical evaluations necessary to determine whether they are a suitable candidate.

That said, I have no regrets about my cochlear implant. It has given me tremendous satisfaction. The ability to once again communicate with my family and friends without depending on an interpreter or lipreading solely has been overwhelming. To be able to use the phone and talk with people I have not talked with in years, is beyond description. For me, going to Mayo Clinic and choosing implantation was the right decision. I am grateful to the scientists who have developed the implant, to Cochlear Corporation for researching advances and manufacturing the implant, and to my doctor and audiologist at Mayo for all of their support.
It has been said that becoming deaf after a lifetime of being able to hear can be a devastating experience. It impacts us socially, educationally, vocationally, psychologically and spiritually. Becoming deaf due to Neurofibromatosis Type 2 (NF-2), a life threatening, chronic and progressive neurological disorder, compounds the adjustments that we have to make.

With this medical diagnosis, our lives are repeatedly disrupted by medical interventions; and our self identity, body image and capabilities are altered in ways that other ALDA members may not experience. For example, if we want to learn to use American Sign Language (ASL), we may not be able to do so smoothly, as our hands and fingers are affected by NF-2. Facial expression, a key component of ASL, may be impaired or absent. These problems seriously affect our communication skills. Our panelists will share their experiences and discuss how they have found some level of balance or quality in their lives.

INTRODUCTION

The very first ALDAcon was held here, in Chicago, back in 1989. There were 42 people in attendance, all of whom had lost their hearing as adults, and many of whom had lost their hearing due to NF-2. In fact, it was a person living with NF-2 who got the ball rolling.

After becoming deaf, Kathie Hering looked for literature about deafened adults. She looked for some kind of support group for deafened adults. She found neither. She believed, however, that there OUGHT to be one and set out to get one set up in the Chicago area. She succeeded.

One of the people who attended the support group was Bill Graham, who later had a party for deafened adults and, in due time, wrote a long letter to each member of the group asking that they stay connected. Kathie and Bill had no grand designs in mind! There were many people involved getting ALDA off the ground, but people living with NF-2 were at the center of the effort.

ALDA has changed over the years. Many of our members are hard of hearing, or were deafened at an early age. But, they identify with our life experiences of marginality (where do we “fit-in”) and self-identity (deafness is not central to our self identity).

ALDA’s membership has always had a sizable portion of people living with NF-2. Everyone agrees – that becoming deaf is a devastating experience – like an earthquake, it shakes everything up. Living with NF-2 means that adjustments are necessary. I am reminded of a joke Kathie told me. Remember Fred Astaire? He was famous for his creative and amazing dance skills. We don’t hear as much about his famous dance partner, Ginger Rogers. Think about it, she had to do everything Fred did in 3” heels and backwards! Those of us who have NF-2 are a lot like that. We do everything “in 3” heels and backwards.’

We don’t have much time together this afternoon. In order to help us stay focused and use our time well. I developed some “structure.” I will call them rules.
WORKSHOP RULES

1. **NO MED-SPEAK.** The first few rounds with doctors, surgeons and other specialists exposed us to Med-speak, we learned it fast. We became proud of our new language.

2. **NO LABELS.** Well-meaning friends and family sometimes give us labels like challenged, coping, inspiring, courageous, strong, or brave. These, or any form of these words, are prohibited today because they are labels. Labels go on jars. They are limiting, restrictive and hard to live with or up to. They are also value judgements which tell more about the needs of those who use them than anything else.

3. **NO COOKBOOKS OR RECIPES.** The “my problem and how I solved it” approach may work in some situations, but people living with NF-2 have too many variables to deal with. What helps one person reduce stress may actually create it for someone else.

4. **NO SUGAR COATING OR LEMONADE.** No one has ever said that living with a chronic and progressive condition is easy. It isn’t. Statements such as, “Oh, don’t worry about how you look ... what's inside is more important” are not helpful. We have the right to feel bad.

5. **NO GAMES.** I can’t say how many times people whom I’ve never met before have asked me how many tumors or surgeries I have had. First of all, it’s no one else’s business. What difference does it make, anyway? No one has “it” easy. NF-2 is not fair to anyone. No one will get extra credit or a medal for special hardships.

LIVING WITH NF-2

Let’s look at how NF-2 is diagnosed. According to the NIH’s Acoustic Neuroma Consensus statement (1991) NF-2 may be diagnosed when one of the following is present:

- bilateral 8th nerve masses seen by MRI with gadolinium.
- a parent, sibling or child with NF-2 and either unilateral 8th nerve mass of any other the following:
  - neurofibroma
  - meningioma
  - glioma
  - schwannoma
- posterior capsular cataract or opacity at a young age

That medical jargon doesn’t tell you anything about living with NF2. It doesn’t even mention the stuff we have to deal with on a daily basis – like dry eyes and artificial tears and lubricants to prevent vision loss, or dry mouths that cause teeth problems or chewing and swallowing problems. And that’s just the small stuff!

We are the experts on NF-2! We know there is no cure and that it is progressive. Truth is, we know all we need to know about it. It is very hard to live with but, we have no choice. We must figure out some way to get through the ordeals. We do! But, after the vomiting stops, the IV’s are removed, we leave the hospital, and our hair starts growing back, then what?

The purpose of our time together today is to share with each other some positive and empowering ways to deal with NF-2. Cindy, Fred, Cindy and I believe that even though NF-2 disrupts our lives,
dreams and goals, it is possible to have some balance, peace of mind and to enhance the quality of our lives. We are willing so share with you what sustains and enables us to live with it.

Cindy Henrion
My name is Cindy Henrion, I am 29 years old. I live in Florida. I was deafened, from bilateral acoustic neuromas in November of 1992, at the age of 23. Prior to that, I had two surgeries that were successful. Even though my doctor was not very confident after one of my surgeries that I would be able to walk afterwards, I bought a pair of roller blades three months later and learned how to skate – although not very well.

I never knew what NF-2 was until I was nearing my second AN surgery. Once I found out what NF-2 was, I was scared and depressed. After I became deaf, I went through all of the stages of grieving, only I did not know what was happening. I suffered insomnia, anger, depression ... the works. I felt very alone until I got the idea to try to find a pen pal who was deafened like myself. I wrote Cindy Schneider; and we wrote long and frequent letters.

Some people live paycheck to paycheck; well, do that, too but, I was living from MRI to MRI! I decided that I was tired of not living at all, by worrying about things that I have no control over.

Cindy was great to me but, I decided that I needed some local friends. I became very involved with our local ALDA chapter. I edited the chapter newsletter which was therapeutic for me because I love to write. I attended group counseling with other deafened adults and that, too, was very helpful to me.

I work full time for the Florida Department of Revenue. I am their “token deaf person.” I am also taking college courses in the hope of getting a degree. I am learning web page design and planing on doing a web site for our ALDA chapter. I keep myself very, very busy with work, school and ALDA. Other things I do that helps me is working out and taking care of my dogs.

Fred Getz
Hi, I am Fred Getz and I have been deaf for 20 years due to NF-2. I am married, and we have three kids. I work as a Software Engineer for Lockheed Martin. We create submarine sonar trainers for the Navy.

Living with NF-2 sure can be tough sometimes. However, there's so much more to life than dwelling on NF-2. Instead of talking about what NF-2 has done to me, I prefer to talk about what I have done, despite NF-2. My wife has been a rock of support for me and we have three wonderful children. Two of them have NF-2. That is difficult but, we all provide support for each other. Donna and I knew the odds regarding our children having NF-2. Looks like we beat the odds, just in the wrong direction.

What do I do to cope with NF-2 and how do I manage to make the best of this mess? I try to keep a sense of humor. I lean on friends and family. I help others. I use technology, especially computers. I continue my education. I also stay busy and have faith in God.

Cindy Schneider
I live in Ohio, I am single and I have a 17-year-old son. I became deaf in 1986. My son was five at the time we began learning Sign Language together. The first year of deafness was isolating and I relied heavily on a couple of good friends who learned to sign with us.
In 1987, a spinal tumor slowed me down a little and I spent a lot of time writing to people. I wrote 20 or so letters a week! ALDA was just starting to take shape in Chicago, but I felt it was too far away to benefit me. In 1988-92, I went back to college and that did wonders for my self confidence, it allowed me to focus the future. Within six months of graduating, a spinal tumor caused more leg weakness and I began using a wheelchair. It was a really depressing year. Friends and faith got me through it. I read a lot of positive books focused on "WHAT NOW" instead of "WHY."

In 1994, the tumor was removed but, the damage had been done. I still use a wheelchair to get around. I got into exercising regularly and that has been a big plus in my life. I love it and it shows me what I can do.

With NF-2, there are good days and bad days. "This too shall pass" is often repeated when those bad moments come up. Again, my support system of friends and family is important to me. I try to think of what I can do, instead of what I can't. I try to be hopeful. If today is lousy, there is a good chance tomorrow will be better.

I teach Sign Language to kids and adults. I am also very involved with my church, and I exercise at the YMCA 4 or 5 times a week. I get involved with groups like "NF-2 Crew" and ALDA to prevent myself from becoming isolated and to keep busy.

Mary's 2 Cents Worth
One thing I have learned about myself is, "I MUST" laugh, or I become sick. I have two collections. One for music and one for laughter. I have a scrap book full of funny pictures, stories, joke, and cartoons. I call it my "Yuck Book."

SUMMARY OF PANELIST'S PRESENTATIONS
I think we can draw conclusions from what the four of us have shared.

1. Take Charge! Our doctors and surgeons do not know everything and they certainly do not hold all the cards — it just feels like it sometimes. Also, even if an activity requires a lot of effort and energy on your part, do it anyway. You will feel better!

2. Lighten up! What do you enjoy doing? What makes you feel good about yourself? Get involved with hobbies, pets, learning new skills. Take time to play!

3. Get involved! Like John Kennedy said, ask not what ALDA or the NF-2 crew or NF Inc. can do for you, ask what you can do for them. Do things for others: volunteer to work in hospitals, your local humane society, or your church/temple. It will make you feel better.

4. Set Goals! For the short term: Have a daily routine and try new things a little at a time. For the long term, think about vocation and education. Learn something new!

5. Spirituality!
   - Family and Friends
   - Faith and Trust
CONCLUSION

ALDA gives all of us choices about communication that did not exist before. It gives us a home where we can feel comfortable and comforted. What started out as a small support group that was set in motion by a person living with NF-2, developed into a new lifestyle. Bill's party had 13 people in attendance, none of whom knew each other, none of whom signed fluently, none of whom could lip-read well either! They found other ways to communicate and had a great time. After the party, they stayed in contact. It just kept growing by leaps and bounds. It became an international organization, with a published newsletter and a big, big party called ALDAcon.

NOW, BACK TO YOUR FUTURE, 3" HEELS AND ALL! STRESS BUSTERS!

Take care of yourself! Just about any book or magazine that you pick up these days offers an article or two on stress reduction and the mind/body connection. For some medical conditions there is a direct linkage to lifestyle, diet and exercise. We know, for example, that lung cancer can be directly connected to smoking. NF-2 is genetic; a good diet and regular exercise help us tolerate the changes. There's an old saying that, "You can't keep trouble from coming but, you need not give it a chair to sit on."

Diet: food is fuel! You can't expect your car to run right without gas or oil. You can't expect your body to run well without the proper fuel.

Exercise: Exercise releases chemicals in our brains to alleviate depression. Get moving!

Pets: Pets give us unconditional love, and besides making us play, laugh and relax, petting them lowers our blood pressure!

Hobbies: Do what you enjoy, gardening, reading, writing, collecting, volunteer work, churches, hospitals, humane society, Lions Club. Learn something new and keep those brain cells moving, as the saying goes, "Use it or Lose it."

Keep a journal: Write to yourself, "This is for YOUR eyes only."

Psycho-therapy and medication for depression: Often a crisis will bring up old and unresolved stuff. A good therapist can help you work it through. If you go through some rough spots or if you get stuck in the adjustment process you may, like many others, benefit from medication for depression. Medication has improved, and now has fewer side effects. We don't need depression on top of everything else.
SUGGESTED READING:


LIPREADING MADE EASIER THROUGH CUED SPEECH

Rosemary R. Walton and Frankie Lange

When people lose their hearing as adults, they look for ways to continue communicating. They may assume that lipreading will easily fill in the sound gap but are often surprised and discouraged to find that, even with lessons, lipreading is not an easy thing to do after a lifetime of paying attention to the sounds of a language with no thought of how those sounds might look on the mouth.

CUED SPEECH AS A SOLUTION FOR THE DIFFICULTIES OF LIPREADING

The system of Cued Speech, which uses a few hand signals along with the mouth movements that speakers normally make, can clarify what is indecipherable through lipreading alone. For English speakers, it makes English entirely visible. Cued Speech can offer relief from the uncertainty and guesswork of lipreading and may even help people to improve their skills in lipreading without the hand cues. This presentation will consider the problems of lipreading that are resolved by Cued Speech, analyze the way English looks on the mouth, and offer a bare bones outline of the cues and their use in making English visible.

DIFFICULTIES OF LIPREADING

When we talk about lipreading, we are speaking about the way sounds "look" on the mouth. Strictly speaking, sounds are not visible — they are audible. What we are looking at are the mouth movements that are required to make speech sounds. The difficulties of lipreading occur because of the way our mouths move to make sounds in English.

There are three main problems for lipreaders: (a) many sounds look alike on the mouth; (b) some sounds are not visible on the mouth at all; and (c) the speed of normal conversational speech changes lip movement.

The most obvious example of "look-alike" sounds in spoken English are the three consonants we make by putting our lips together. The first sound in each of the following words is made with the lips together: pat, bat, mat. The lip movement is the same in all three. Yet, people who are hearing have no trouble telling the difference, because the letters b, p, and m all sound different. They can use those sound differences to distinguish the three consonants. But in lipreading, we are asked to recognize those consonants without the benefit of sound. Since there are many words that sound different but look the same in spoken English, the lipreader is often left to guess.

Other sounds are made by parts of the mouth that cannot be seen moving. The first sound of each of the following words is made at the back of the mouth with the lips slightly open: cot, got, hot. The mouth looks much the same in all three. Sound distinguishes the three different consonants for people who hear, and once again, the lipreader must guess which consonant is spoken or whether there is any consonant at all — possibly the speaker has said a new name, Ott.
The third difficulty for lipreaders is the speed of normal conversation. The mouth does not hold a position for long in running speech, and words are run together in ways that blend word boundaries and sometimes make it hard for the lipreader to identify individual words in a sentence.

The consequences of such difficulties are felt by many who have tried to develop lipreading skills. Failure to understand can easily cause feelings of foolishness and discouragement. Too often, such feelings cause people who are deafened later in life to withdraw from social interaction, to live in an isolation they would not have chosen if they could hear better. If only English could be made more visible. If only every sound could be visible and could look different from every other one.

**CUED SPEECH AS A SOLUTION**

A little over thirty years ago, in 1966, Dr. R. Orin Cornett invented a system that can make English entirely visible (Cornett & Daisy, 1992, p. 747). He devised Cued Speech as a way to allow young children who are deaf or hard of hearing to learn English naturally at home, specifically to prepare them for reading English.

Though Cornett may not have had late-deafened adults in mind when he developed his system, his work may be one answer to the difficulties of lipreaders. The Cued Speech system for American English uses hand signals in combination with the mouth movements normally used by English speakers. The hand signals identify sounds that are not visible on the mouth and distinguish sounds that look alike on the mouth. Cued Speech keeps the number of hand signals low by using one hand cue for three or four sounds that have different mouth movements. There are just eight handshapes to show all consonants; there are four positions at which the hand is placed to show all the vowels.

The mouth cues, which are the visible mouth movements of spoken English, are combined with the hand cues, the hand positions and shapes. With the combination of mouth and hand cues, a person can cue or cueread any sound, syllable, or word of English.

**APPEARANCE OF ENGLISH ON THE MOUTH**

In order to show most clearly what the hand cues of Cued Speech add to lipreading efforts, it is useful first to examine the appearance of spoken vowels and consonants on the mouth. Frankie Lange has developed descriptions of the mouth movements seen when each sound is spoken. As you attempt to lipread or cueread, you will observe a few basic features of mouth movement identified by Lange: (a) the lips move forward and backward; (b) the lower jaw moves up and down; (c) the upper jaw remains stationary; (d) the tongue may be somewhat visible.

Visible vowels. Lange groups vowels according to their visibility. She describes six as visible vowels. The phonetic notation used below was developed by Dr. Walter Beaupre for his book, *Gaining Cued Speech Proficiency* (1984). Lange's descriptions of the visible vowels follow: /ee/, as in see, me, team — lips move backward as far as they ever will; /ur/, as in fur, her, burner — lips circle, slightly separated in center; /aw/, as in dawn, ought, ball — lips circle forward, then relax; /ue/, as in Sue, flew, moon — lips form a small, tight circle; /oh/, as in oh, go, sew, though — lips form a circle; /ah/, as in Mom, father — lower jaw drops down as far as it will ever drop.

Another set of visible vowels is two-part vowels called *diphthongs*. As each diphthong is spoken, the mouth changes from one position to another to make the two parts of the sound: /ay/, as in play, weigh, mail — lower jaw moves down a little, then comes back up slightly; /oi/, as in boy, oil — lips circle forward, then go backward; /ei/, as in eye, lie — lower jaw moves down about as far as for /ah/.
but lip movement is seen at corners of mouth as lips start to move back up; /ow/, as in brow, sound — lips move backward and then circle forward.

For lipreading practice, Frankie Lange recommends that people say the visible vowel and diphthong sounds to themselves for ten minutes a day in front of a mirror, for at least two weeks. She believes firmly that such practice makes it possible for a person to learn to distinguish between those vowels on the lips of other people.

**Invisible vowels.** Lange identifies the five remaining vowels as invisible vowels, which are hard to distinguish from one another: /e/, as in fed; /o/, as in look, put; /i/, as in fit; /a/, as in back; /uh/, as in nut. She observes that with these vowels the lips are only slightly parted, making them hard to tell apart. The words bet, put, bit, bat, and but, which differ primarily in vowel sounds, are hard to distinguish on the lips.

One final vowel sound that is particularly hard to lipread is a neutral vowel sound known as the schwa. Speakers of English use the schwa in unstressed syllables that are spelled with any of the five vowel letters. The following words are all spelled with different first vowels: alone, enough, illusion, and upon. In the course of relaxed conversation, a person is likely to say all the first syllables as an unstressed /uh/. To the lipreader, these invisible vowels, whether stressed or unstressed, all look much the same.

**Look-alike consonants.** We usually consider that consonants can be distinguished by lip shape or tongue placement, but as observed earlier, many consonants have look-alikes. The lipreader needs to be aware of possible confusions in the following sets of look-alike consonants: /p, b, m/, as in pack, back, Mac — lips press together and open—these are the consonants Frankie Lange calls "muppet mouths"; /f, v/, as in fan, van — lower jaw moves up and upper teeth rest on the lower lip; the two th sounds, /xh, th/, as in thigh, thy — tongue may be seen at or between teeth; /sh, zh, ch, j/, as in thresher, treasure, chest, jest — mouth takes on a squared appearance; /w, wh/, as in witch, which — lips move forward to form a circle and then move back; /t, d, n, l/, as in Ted, dead, Ned, led — tongue goes to the roof of the mouth and presses behind the front teeth — /l/ has a slightly different shape when it touches; /s, z/, as in sip, zip — teeth close, lips part slightly.

**Invisible consonants.** As observed earlier, the consonants that are formed at the back of the mouth cannot be seen in lipreading: /k, g, ng, h/. All the consonants in hack, hang, and bang are invisible. The lipreader sees only the speaker’s parted lips, which could even mean a vowel is being spoken. The consonant /yl/, as in yes, has no look-alikes. It is usually not visible.

**CUED SPEECH HAND SIGNALS TO CLARIFY MOUTH INFORMATION**

This review of the visibility of English sounds indicates most of the causes of lipreading difficulty. Because of mouth movements that are invisible or that produce more than one sound, only about 30% of English words spoken in isolation can be understood with any certainty by looking at the lips (Cornett & Daisey, 1992, p. 183). Cued Speech, on the other hand, can make all sounds visible and eliminate the confusion of look-alikes by combining hand signals and mouth movements.

When the consonants /p, b, m/ are spoken, the lipreader sees only the lips pressed together. In cueing, a distinctive handshape is combined with the lip shape to show each sound (handshapes illustrated in Figure 1): for the /p/ in pea, we use handshape 1, with one finger extended; for the /b/ in bee, handshape 4, with four fingers extended; for the /m/ in me, handshape 5, with all five fingers extended. A person who has learned the significance of the handshapes and who already knows
Figure 1

Cued Speech Vowel Code

- Mouth
  /ee/ /ur/
  See her.

- Chin
  /aw/ /e/ /ue/
  Dawn fed Sue.

- Throat
  /u/ /i/ /a/
  Put it back.

- Side
  /uh/ /oh/ /ah/
  Uh-oh, Mom!

- Chin-throat
  /ay/ /oi/
  Playtoy

- Side-throat
  /ie/ /ow/
  Time out!

Cued Speech Consonant Code

1. /d, p, zh/
   Don't pat Za Za!  
2. /k, th, v, z/
   Cut the valentines.
3. /h, s, r/
   He saw red.
4. /n, b, wh/
   Nice big whales

5. /m, t, f/
   Mittens touch fingers.
6. /l, sh, w/
   Lamb, sheep, wool
7. /g, j, xh/
   Go jump through.
8. /ch, y, ng/
   Choose your ring.

the significance of the lips' pressing together, can cueread the differences between these words: pea, bee, me.

Similarly, hand signals of Cued Speech can show sounds like /k, g, h/ that are completely invisible on the mouth. The lipreader sees only parted lips when these sounds are spoken. In cueing, a distinctive handshape is combined with the parted lip shape to show each sound clearly: for the /k/ in cot, we use handshape 2, with two fingers extended; for the /g/ in got, handshape 7, with two fingers and the thumb extended; and for the /h/ in hot, handshape 3, with three fingers extended. A person who has learned the significance of these handshapes can cueread the invisible consonants in the words cot, got, and hot.

Hand signals can also clarify which vowel is being expressed when the shape of the mouth is hard to read. The vowels in the words pet and pit sound clearly different to a listener. If sound is eliminated, however, a lipreader might easily confuse the words because differences in mouth shape are so slight. In cueing, the placement of the hand at a particular position combines with mouth shape to indicate vowels.

The hand is placed at the chin for pet, and at the throat for pit. In that way, vowels that look much alike on the lips alone are made to look different by hand placement. When the cues for the individual sounds are grouped, they can form syllables, words, and sentences of English — or another language — so that a cuereader can see English on the lips and hand of the cuer. Though the lips move during cueing, there is no need for sound to be heard or even produced by the cuer. The cues are entirely visible.

**BASICS OF THE CUED SPEECH SYSTEM**

Keeping in mind the idea that, in cueing, mouth and hand work together to make English visible, we can begin a catalog of the cues of cued English and discover how to cue words. To show vowels, a cuer moves the lips and places the hand at one of four places: beside the mouth; at the center of the chin; at the throat; or beside the face. To show consonants, a cuer moves the lips and assumes one of eight handshapes, extending one or more fingers. Either hand can be used for cueing. The information is the same, whether presented on the right or left. So that the cueing hand can touch the face, the forearm is held at about a 45-degree angle. The wrist is kept straight; the palm is parallel to the body; and the back of the hand always faces out. The idea is to make the cues absolutely clear to the cuereader.

**FIRST VOWEL POSITIONS AND HANDSHAPES**

Finally, we are ready for the first cues. We will begin with vowels. Vowel cues are named according to their placement (vowel placements illustrated in Figure 1). The two vowels cued at the mouth are called mouth vowels. They are the sounds /eel/ and /url/, as in See her (Rupert, 1996). You may ask how two vowels can be cued at the same place. Won't they be confused? Cueing before a mirror will show that these two vowels look different on the lips. For the vowel in see the lips are drawn back; for the vowel in her the lips move forward, rounded. In reading cues, when you see the hand at the mouth, it is clear that the vowel can only be /ee/ or /ur/. The lips tell which of them is being cued. The vowels /eel/ and /url/ are spelled in many ways in English: wheel, please, chief, burn, work, verb, first. However, since the cues show the sounds, it is the sound you will concentrate on, the way you would normally say it, rather than the spelling.

To cue just the vowel /eel/, open the hand fully, with fingers and thumb extended, fingers together, palm flat, to form the open handshape 5, so called because you use five fingers. Touch the tip of
your middle finger at the corner of the mouth as your mouth forms /ee/. No voice is required, but lip movement is a necessary part of the cue. To cue the vowel /ur/, make the same handshape and touch the same mouth position while mouthing /ur/. Any time these vowels occur in a word, your lips will form the appropriate shape and your hand will touch at the mouth position. These two vowels look different to a cuereader because the lip shapes are different.

**Handshape 5** is used when vowels are cued by themselves or when a vowel comes at the beginning of a word. It is also used to show three consonants, /m, t, f/, as in Mittens touch fingers (Koehler-Cesa, 1990). That is a good memory device, because handshape 5 looks like a mitten. Any time the consonants /m/, /t/, or /f/ occur in a word, your hand forms handshape 5. You may ask how one handshape can be used to cue vowels by themselves and three consonants. Won’t the sounds be confused? Mouth shape prevents confusion. The mouth is open when the vowel /uh/ in up is cued; the mouth takes a different shape for each consonant when the nonsense syllables /muh/, /tuh/, /fuh/ are cued. When the cuereader sees handshape 5, it is clear that a vowel or one of the three consonants /m, t, f/ is being cued. The lips show which one. For this reason, it is very important to practice cueing before a mirror, in order to become familiar with the way both hand and mouth look. While learning to make the hand cues, you will also be learning to cueread and lipread.

**Handshape 3** is used to show three other consonants: /h, s, r/, as in He saw red (Rupert, 1996). To form handshape 3, place thumb and index finger together, as in the common “A-okay” sign. The three fingers are straight and together; the back of the hand faces out. Any time the consonants /h/, /s/, or /r/ occur in a word, your hand forms handshape 3. It can be used for all three because the mouth takes a different shape for each consonant. In reading cues, when you see handshape 3, you will know the cuer is cueing /h/, /s/, or /r/. The lips will tell you which one is being cued. It is important to note that the /r/ sound in red, which is cued with handshape 3, is a consonant. It is not the r-like vowel sound in “I heard a bird.”

**CUEING A WORD**

Using handshapes 3 and 5 and the mouth vowels, we can cue several words like her and me. First think of the beginning consonant in her - /h/. Form the handshape for /h/ - handshape 3. Then think of the vowel in the word her - /ur/. Recall where it is cued - at the mouth position. Place the consonant handshape 3 at the mouth position as your mouth forms “her.” To cue me, think of the handshape for the beginning consonant /m/ - handshape 5. Then think of the vowel /ee/ position – the mouth. Place handshape 5 at the mouth position as your mouth forms “me.”

These two words illustrate what is sometimes known as the consonant-vowel rule, or CV rule. The consonant handshape is placed at the position of the vowel that follows it – /h-ur, m-eel/. We often say that the consonant “goes to” the vowel position. Using the CV rule, we can cue words formed of the mouth vowels /ee, ur/ and handshape 3 or 5 consonants: see, sir, tea, fee, fur, he. In each word, the initial consonant handshape is placed at the position of the following vowel.

Many words and syllables end with consonants, as well. Consonants that have no following vowel, like those at the end of a word, are cued at the side position. Side position is level with the mouth, beside but not touching the face. To cue the word heat, begin by cueing the first part, /hee/, with handshape 3 at the mouth position and your mouth forming the vowel. Then move the hand to the side position and make handshape 5, as your mouth forms the final /t/ sound. Because you must coordinate the mouth and hand, when you are first learning, you may have to pause your mouth movement while you think of the next thing to do with your hand: /hee t/. To cue the word firm, begin by cueing /fur/ with handshape 5 at the mouth as your mouth forms the first part of the word. Then move handshape 5 to the side position as your mouth forms the final /m/: /fur m/.
Now you know enough to cue several words that end with consonants: seat, hurt, term, meat (/see t/, /hur t/, /tur m/, /mee t/). Note that although the words her, sir, and fur are spelled with a final r, it is not necessary to cue the /r/ handshape. The vowel in these words is the r-like vowel /ur/, and no consonant cue follows it. The entire word is cued with the first consonant handshape placed at the mouth (/hur/, /sur/, /fur/).

Words that have more than one syllable, like heater, are cued following the CV rule: the consonant before the vowel in each syllable is cued at the syllable’s vowel position. The two syllables of the word heater are /hee/ and /tur/. The first syllable is cued with handshape 3, placed at the mouth: /hee/; the second syllable is cued with handshape 5, placed at the mouth: /tur/. As you cue each syllable, tap the vowel position with the appropriate handshape. The word heater will require two taps: /hee tur/.

Some words have two or more consonants clustered together, as in feast, free, and street. You have already heard about the CV rule, that a consonant handshape is placed at the position of the following vowel. In clusters, some consonants are not followed by vowels. Those “extra” consonants are always cued at the side position. When a cluster occurs at the end of a word, as in feast, both consonants are cued at the side, because neither one has a following vowel: /fee st/. When a cluster occurs at the beginning of a word or syllable like free or street, one consonant follows the CV rule and is cued at the vowel position: /ree/. The consonants that come before it, because they are not followed by vowels, are cued at the side: /f ree/, /st ree t/.

Now you have heard the basic instructions for cueing any word. What remains is to learn the positions for the other vowels and the handshapes for the other consonants. Normally an instructor spends two or three hours teaching the information just outlined for you and then spends another six or eight hours teaching the remaining cues and providing practice opportunities.

**REMAINING VOWEL POSITIONS**

Three vowels are cued at the chin position: /aw, e, uel/, as in Dawn fed Sue (Rupert, 1996). As a memory device, you can imagine Dawn feeding Sue; touching the chin position is similar to the feeding motion. The chin vowels look different to the cuereader because the mouth shapes are different. These sounds are spelled many ways in English: bought, mall, cause, head, said, new, do, fruit. Using handshapes 3 and 5, we can cue a few words that have chin vowels: saw, moss, met, test, Sue, roost.

Three vowels are cued at the throat position: /oo, i, a/, as in Put it back. Two of these sounds, too, have many spellings: foot, would, hymn, build, hear. Theoretically, /oo/, /i/, and /a/ look different from each other to a cuereader because the mouth shapes can be slightly different. However, in rapid speech they can look much the same, causing problems. They are three of the vowels that Frankie Lange identifies as invisible and hard to distinguish. We can cue a few words that include the throat vowels: soot, foot, rim, mist, ram, staff.

We have been cueing final consonants and parts of clusters at the side position. The same side position is used to cue three vowels, as well: /uh, oh, ah/, as in Uh-oh, Mom! (Koehler-Cesa, 1990). Here are some of the ways these vowel sounds are spelled in English: cut, some, the, above, know, beau, sew, Bach, not, heart.

To make the vowel cues look different from consonants cued at the side, small movements are added. The arrows on the cue chart will remind you of those movements. To cue /uh/, drop the hand downward from the side position about one half inch, in what is called a side-down movement.
To cue /oh/ and /ahl/, move the hand forward about one-half inch from the side position in what is called a side-forward movement. These two vowels can look different to a cuereader because the mouth opens wider for /ahl/. To cue a consonant that follows a side vowel, return the hand to the basic side position. We can cue words containing side vowels: rough, fuss, oat, toast, hot, far.

When vowels are spoken in unstressed syllables, like the first vowels in alone, enough, illusion, and upon, they are often pronounced as the neutral vowel, schwa. Since schwa sounds something like an unstressed /uh/, cuers use the side-down movement. The schwa in the word afar and the phrase a toast are cued with a side-down movement.

The cues for some two-part English vowels called diphthongs involve two vowel positions. The cues for the chin-throat diphthongs /ay/ and /oi/, as in playboy, begin at the chin and move to the throat position. As the hand moves, it may change handshapes. The handshape of the consonant preceding the diphthong touches the chin, and the hand opens to a vowel handshape 5 at the throat. With the chin-throat diphthongs we can cue hate, race, Roy, and Royce. The cues for the side-throat diphthongs /ie/ and /ow/, as in time out, begin at the side and move to the throat position. To cue words containing these diphthongs your hand assumes the preceding consonant handshape at the side and opens to handshape 5 at the throat. We can cue time, right, how, and house.

The cues for all the vowels in English have now been described. You cannot have learned to cue every vowel; a person cannot learn this information so quickly. But you probably understand the idea of cueing vowels: mouth and hand position together show a cuereader what vowel is being cued. Before we tackle the consonants, we can cue a little of the alphabet, using the cues presented thus far.

Note that the letters F, M, and S, are cued as if their names begin with the letter e as in egg. The names of all these letters can be cued now: A, C, E, F, I, M, O, R, S, T.

**REMAINING CONSONANT HANDSHAPES**

There are six more consonant handshapes that complete the Cued Speech system.

*Handshape 2* is used to show four consonants: /k, th, v, z/, as in Cut the valentines. Note that the letter s in valentines is spoken and cued /zl/, like the letter z. To form handshape 2, extend the index and middle fingers. Hold the others out of sight with your thumb. The fingers are straight, with the back of the hand facing out. As a memory device, consider that the two fingers look like a pair of scissors used to “cut the valentines.” The handshape 2 sounds all look different on the lips, as in the words cat, vat, that, and the names of the letters v and z. Speaking of the names of letters, with handshape 2, you can cue the letter x. Think of how the name is pronounced. It has three sounds: /el/, /k/, /l/.

With knowledge of this third handshape you can begin to see how Cued Speech can clear up the lipreader’s confusion about look-alike and invisible sounds. The words fat and vat look the same on the lips, as do the names of the letters c and z. In the words hat, cat, and at, invisible consonants begin two words, but all three look like they could begin with vowels. With handshape cues, all becomes clear. The word fat begins with handshape 5 and lower lip touching teeth; vat begins with the same lip movement, but uses handshape 2. The cuereader sees a difference in handshape. The word hat begins with handshape 3, and the lips slightly parted; cat has parted lips with handshape 2; at has parted lips and handshape 5, because it begins with a vowel. Sounds that are hard to see or that look the same on the lips look different on the hand.
Handshape 4 is used to show the consonants \(n, b, wh/\), as in *Nice big whales* (Rupert, 1996). To form handshape 4, curl the thumb down out of sight and hold the four fingers straight and together, the back of the hand facing out. You can see that handshape 4 consonants all look different on the lips in the words *knee, bee, whee*. This new handshape lets you tell the difference between other look-alikes. *Mat* and *bat* can now look different; so can *nick* and *tick*.

Handshape 1 shows the consonants \(d, p, zh/\), as in *Don't pat Zsa-Zsa!* (Rupert, 1996). To form it, extend only your index finger with the back of the hand facing out. As a memory device, imagine shaking your finger at a child as you insist, "Don't pat Zsa-Zsa!" Handshape 1 sounds all look different on the lips: *deck, peck, bayed*, and *beige*. More look-alikes can now look different. The first sounds of the words *may, bay, pay*, look alike on the lips, but three different handshapes make them look different. The final sounds look alike on the lips in *kraut, crown*, and *crowd*, but three different handshapes make them look different.

Handshape 6 shows the consonants \(l, sh, w/\), as in *lamb, sheep, wool* (Rupert, 1996). To form it, point the index finger and raise the thumb in an L shape. Remember to keep your wrist straight, the back of your hand facing straight out. All handshape 6 sounds look different on the lips, as in the words *Lee, she, we*. This handshape clears up further look-alike confusion. Now the words *nine, dine, line* can all look different — on the hand. Knowing that handshape 6 is used in cueing \(/sh/\), a cuereader can tell the difference between the word *shock* and the French name *Jacques*.

By this stage, a cuer can also name most of the letters of the alphabet. The consonant \(L\), using handshape 6, is cued as if it begins with the vowel \(/e/\; /el/\). The letter \(Y\) is also cued using handshape 6, as its name begins with the \(/w/\) sound. Try to cue more of the alphabet: A, B, C, D, E, F, I, K, L, M, O, P, R, S, T, V, X, Y, Z. After learning only two more consonant handshapes, you will have all the information you need to cue the whole alphabet and any word in the language.

Handshape 7 shows the sounds \(g, j, xh/\), as in *Go jump through* (Rupert, 1996). It is formed by pointing the first two fingers and raising the thumb high. One finger is added to handshape 6, to make handshape 7. Now you can cueread a third invisible consonant, in the word *goal*, for example. The look-alike words *hole, coal*, and *goal* begin with handshapes that show different invisible consonants: *hole* (3), *coal* (2), *goal* (7). Now the words *back* and *bag* can look different, and the difference between the look-alikes /sh/ and /j/ in *shade* and *jade* is clear.

You can also see the difference in the two th sounds. They can be hard to distinguish in lipreading. Unfortunately the cues can be hard for people to remember, too, so you may need to be flexible with yourselves and others. The voiced th sound heard in *the, this*, and *that* is cued with handshape 2 — remember — "Cut the valentines.." The unvoiced th heard in *through, thick*, and *thumb* is cued with handshape 7. It is written with the symbol /xh/ in your practice materials. It may help to remember that to cue the word *thumb*, your thumb is raised, forming handshape 7. To cue the other th, the voiced sound in *the*, use handshape 2, in which the thumb is not visible.

Handshape 8 shows the final three consonants of English: \(ch, y, ng/\), as in *Choose your ring* (Rupert, 1996). It is formed by making a reversed victory sign. That is appropriate after this marathon effort. Spread your index and middle finger into a wide V shape with the wrist straight and the back of the hand facing out. To cue handshape 8 at the mouth, as you would in the word *cheat*, touch the mouth position with the middle finger. To cue at the chin or throat, as you would in the words *you* and *chat*, touch with the index finger. The object is to keep the other finger from covering the lips.
With the addition of handshape 8, you can now cueread all invisible and look-alike consonants. The words back, bag, and bang can all be seen. The words cheap, sheep, and jeep can look different. You can cue all sorts of words ending in ing: seeing, talking, getting. And you can cue the name of what you have been learning here – cueing. Believe it or not, handshape 8 is needed twice to cue the word cueing. It starts with /k/ and then sounds like you: /k yue i ng/. You also have the information needed to cue the whole alphabet. The letter name most difficult to cue uses handshape 8 – the letter W: /duh bl yuel/.

In learning to cue, try to give yourself a few minutes of regular mirror practice each day, familiarizing yourself with the appearance of the mouth movements of spoken English and with the combination of mouth and hand cues. If you and a partner can also practice together, all the better – but still do mirror practice. Try having your cueing partner first use cues just for single words that have been hard to lipread. You may find that an occasional cued word is all you need to keep you in touch with conversaion you can generally lipread.

Materials that may help you are available from Cued Speech Discovery cuedspdisc@aol.com, a service of the National Cued Speech Association. That office can also inform you of regional organizations that are ready to answer the questions you will certainly find yourself asking.

REFERENCES


DEAF AND HEARING: A BARREL OF LAUGHS

Fred Heppner and Cheryl Heppner

In this workshop, stories were shared about humorous situations that happened to late-deafened people in their ongoing, frustrating, but always interesting, interactions with hearing people of all kinds.

WATER LEAK STORIES

Cheryl Heppner:
We have log a cabin in West Virginia. About five years ago, Fred had to work late, so I drove out by myself in the morning. When I arrived at the cabin, I went down in the basement and turned on the main water supply from our well. Then I went back upstairs, where I put things away, played with the dog, and read a book. I noticed that something was wrong when I turned on the water faucet in the kitchen. Water was coming out kind of in drips.

Later when I went to wash my hands in the bathroom, that faucet also gave only drops of water. I waited a couple of hours, checked again, and still didn't have any water pressure in the faucets. So I went back to the basement, thinking maybe I hadn't turned the lever far enough. That was when I found the basement was under 3 to 5 inches of water. We had just had our cabin treated for an insect pest called wood borers. Apparently the workers, who came while we were away, had been thirsty. They pried open a basement window and turned on a faucet to get a drink. Since the main water supply was off, nothing came out, so they did not bother to turn off that faucet. I didn't hear the water start pouring out of the faucet when I turned the water supply on.

Fred was not amused to have a basement pond. To understand the full impact, you must know that this guy is a pack rat. The basement is where he keeps all of his tools and other precious things. All of them were under water. I spent the worst 5 hours of the summer bailing water out of the basement and trying dry off all his things before he got there.

Fred Heppner:
I still haven't forgiven her for that. Every time she goes out to the cabin, I always tell her, "Don't turn anything on!" Every time.

Audience Member:
I have worried about water running since I was a little girl, when I could hear fine. My family was in the car, ready for a trip. I told my parents I needed a drink of water. I ran in and got one, but left the water running. We were gone for a whole week. When we came back to our house, it was just about flooded. Then when I became deaf, it got so much worse. Once I went swimming, and when I got back I wanted to wash the chlorine out of my bathing suit. So I put it in the sink and forgot the water was still running when I jumped in the shower. Water spilled out and ruined our carpet. I thought, "Oh, my husband is going to kill me!" I went out, got a fan, and did everything I could to try to dry it. When he got home, I think he understood that it is really hard to know that you are leaving water running. I think people who hear don't worry about things like that.
Audience Member:
I am the hearing half of our relationship. My partner tends to leave the water running fairly often. So, I keep threatening to get faucets that work like the one in the dentist's office — you have to step on them, and if you step off, the water stops.

Audience Member:
Maybe a year ago, I was getting ready for bed. I turned the light on in the bathroom and thought, "Who spilt that water?" There was a lot of it all over the floor. Then I noticed it was not only in the bathroom, but the hall carpet was wet. One of the grandchildren left the faucet on just a little bit. All I could think about was how the neighbors were going to wonder what I am doing at midnight with every light on in the house.

Audience Member:
We live in the country and have a well. I got up one morning, turned on the faucet, and found we had no water. I flew outside in my nightgown checking the outside faucets. Nothing. I went back down to the basement, where I expected to find the hot water heater out. Nothing. I checked the downstairs bathroom. Seemed okay. I was at wit's end as to why there was no water. Then I checked the bathroom again, and finally thought to take the lid off the toilet tank. Someone had used the toilet and it stuck, pouring water right back down as soon as it filled. It was a day before we got water back.

LEVING THINGS RUNNING

Cheryl Heppner:
I once left my car running until Fred got home and found it. It was probably there about 45 minutes. I was very embarrassed. I only did that once. Another time I left the garbage disposal running for quite a long time and it burned out.

Audience Member:
I left my car running for two days. It had a full tank of gas when it started and was almost empty before anybody discovered it.

Audience Member:
I went to the dentist, and spent half an hour having my teeth cleaned without realizing that I'd left my car running. Not only that, I had locked the keys inside, so I couldn't do anything about it. I tried to reach my husband to get his keys, but I couldn't get hold of him. The police refused to come help me out. The dentist's office finally loaned me a hanger and I managed to pull up the door lock by going through a crack in the window.

Audience Member:
I left an Epilady, a leg shaver for ladies, running on the counter in the bathroom and went about my day. When my husband got home, he heard something strange and was looking all over trying to find what was causing it. By the time he found it, there were sparks jumping all over the place. It had been going for hours and hours.

Audience Member:
One thing I always forget is the kettle. I don't use one anymore. I have burned the bottoms out of so many kettles; now I just use the microwave.


Audience Member:
I am the hearing half. I have a pager. I left it at home one day, inside my bureau, and it was set to vibrate. About every ten minutes the dogs, my wife tells me, were going hyper. She couldn't figure out what in the world was going on until I got home and I went into the bedroom and said, "Is there some kind of animal loose in the bureau?" It had been paging every ten minutes all day.

Audience Member:
We have an alarm in our house that says, "Intruder in the house, intruder in the house!" So I always have to remember to turn it off when I open the entry doors. One day I forgot and went to clean out the garage. The alarm was blasting the neighborhood, and two cops pulled up. I didn't know why they were there. They said, "Good morning, ma'am." I said, "Hi." They said, "Your alarm is going off."

Audience Member:
I quite often will start something in the oven and set the timer. If I go to another floor, I can't hear it. So the timer goes off until I come back upstairs. This has happened so many times that my cat has learned to come and get me when the stove is making a noise.

TURNING SOMETHING ON – NOT!

Cheryl Heppner:
I think many of us deaf people are world famous for our vacuum cleaner stories. You think you have plugged it in, and then you realize it is really not picking up anything. You find it was never on. Or, maybe you didn't realize you pulled the plug out and you kept right on going.

Audience Member:
I was listening to a tape and just couldn't pick it up. So I asked my son for help, and he opened the tape deck. He said, "There is no tape in here."

Audience Member:
I had some clothes I needed for work that I put in the dryer. When I went to get them so I could get dressed, I realized that I never started the dryer.

Audience Member:
I was upstairs, and I thought my kids were playing really loud rock music. I went downstairs, and I screamed at them, "Turn off the music!" They looked at me and said, "Mom, there is no music on!" It was the tinnitus in my head. It was so loud it just felt like there was a rock band going. I thought that they were teasing me. I wasn't satisfied until I went over and checked out the stereo, and it wasn't on.

Audience Member:
Nowadays, everything is done for you automatically, but years ago you had to put film in a camera manually and turn it yourself. When my daughter was one year old, we went to New Orleans. We took pictures everywhere – on the whole trip, on the boat ride, all over. When we got home, we opened up the camera, and found there was no film in it. My husband thought I put film in it, and I thought he put film in it. To this day we don't have one picture to show of our whole trip.
FAMILY FUNNIES

Cheryl Heppner:
I read something recently in the magazine called *Hearing Health* that I thought was funny. A hard of hearing mother and her daughter got into a cab. The mother couldn't understand the cab driver. She apologized and explained she couldn't hear him. And he said, "Oh, that's okay, don't worry about it. I am almost blind myself!"

Audience Member:
My elderly grandfather was given a new electric razor, and he thought it was great. He took it out in the yard, wrapped the cord around a limb of a tree, and shaved with the cover still on the razor. He told us, "My, that was such a smooth shave!"

Audience Member:
My wife is an artist. She has a *Far Side* cartoon posted by the easel in her studio. It is a picture of an artist drawing a picture of a knight in shining armor with one foot in a Red Flyer wagon. The caption says, "How are we coming with that picture of Saint George and the dragon?" Great illustration of a hard of hearing artist.

Audience Member:
Two years ago, I brought my husband to a dinner. It was the 10-year anniversary of SHHH in New York, and happened to be the night that the Yankees were playing in the World Series. In a back room was a TV. Most of the women who belonged to SHHH were at the meeting, and the men were sneaking off into the back room, watching the game instead of being at the meeting. A while later, I told friends about it, and they said, "Why were they watching the Yankee's game in the bathroom?" I said, "It wasn't the bathroom. It was the BACK room."

Audience Member:
My husband and I have a dog that has to go out in the morning. One day there was about a foot of snow outside, and my husband went out with the dog. He closed the door behind him, and he didn't have the keys. He had to go to a neighbor's house and then use the phone to call his sister for a key to the house because I didn't know he was stuck outside.

FUN WITH TRAVEL

Cheryl Heppner:
I have a deaf friend who set off a metal detector. She told her husband, "I set off the theft detector" and he thought she said, "I set off the deaf detector." Now that would be really high tech!

Audience Member:
Two years ago, I went to San Francisco with my late-deafened friend, and it was her first plane flight. We got to the airport, and I asked my friend for her driver's license and her ticket. I gave it to the lady at the counter. When the lady finished with everything and gave the ticket and license back to me, I handed them back to my friend and said, "Gate 64." I turned around to get our luggage and stuff. My friend was putting money on the counter. I said, "What are you doing?" She said, "I thought I owed $8.64."
**Audience Member:**
I know of a family that went traveling with a deaf person. They made all the arrangements for accommodations – vibrating alarms, TV captioning, everything. Somehow there was a change in plans or something that resulted in the deaf person being in the room alone. Later, somebody knocked on the door. The door alarm didn't go off or the deaf person didn't see it, and the rest of the family couldn't get in. They banged and banged on the door, but couldn't get in. Security was called, but couldn't get in either because the door was double bolted.

**Audience Member:**
I went on a business trip and discovered there were no radio alarms or clocks in the room. This was a couple years ago when I still had enough hearing left to turn the radio up real loud and wake myself. So I thought I would try for a wake-up call from the hotel. I get up very early because I am a runner, so we are talking like 4:30 in the morning. Of course, when they did the wake-up call, I couldn't hear the phone ring. The good news was I woke up automatically around 4:30 or 5:00, got dressed, put on my sweatband and stereo headphones. I opened up the door and there were two security guards and a policeman standing there. They had come to check on me since I hadn't responded to my wake-up call.

**Audience Member:**
I was flying back from Washington, and never knew that they had made an announcement on the plane, even though I told everybody I was deaf when I got on. The announcement said we were landing in another city and being routed elsewhere. I was supposed to land about 11 p.m. at night. It was like 1:00 a.m. and we were still flying around. I was wondering what was going on. I thought maybe I hadn't changed my watch back. When we finally landed, I stood up and got all of my luggage together. I looked around and noticed nobody else was getting their luggage. Finally, someone told me, "Put your luggage down. We are not getting off the plane." I found out that all we were doing was refueling.

**SHOPPING**

**Cheryl Heppner:**
Shopping with a hearing dog is always an interesting experience. Fred and I went to this really exclusive mall. We were in a store where they had a whole bunch of CDs and videotapes. When it came time to leave, Fred walked out of the store, and I started to follow him. The security alarm went off. Of course, the store people came running. They checked my bag and nothing was in it. They looked at Dana. All she had on was the blue cape she wears to identify she is a hearing dog and her collar.

**Fred Heppner:**
I had Cheryl stay inside while I called the dog through the security gate. The alarm went off. They checked Dana all over, but couldn't find anything. They finally let us go.

**Cheryl Heppner:**
Fred and I started walking through the mall. We walked for quite a while. Then Fred slowed down and fell behind us to look at something in a store window. I turned around to see where he was and found him looking at Dana and laughing. Dana had been prancing through the mall with her tail wagging back and forth and right on the tip of her tail, stuck to her tail hair, was one of those little security strips. It must have been on the floor, and it stuck to her when I gave her the command to "sit" back in that store.
Audience Member:
I was buying my daughter a prom dress at a mall. I thought they checked and pulled that security detector off. Later, I went in another store. Apparently the detector in that store went off, and I didn't hear it. Everybody is running, trying to catch me. They told me, "Go back to the store where you bought it so they can take it off." It was embarrassing, but funny afterwards.

Fred Heppner:
Yeah, Cheryl did that. She has a nice sweater, at home right now, that has the anti-theft device still attached to it, one of the ones with the metal bar that goes through the clothing. I don't know how many people are still looking for her.

Cheryl Heppner:
Much worse, there is an entire mall in Williamsburg that I can never go back to. I bought something early in the morning and they didn't remove the anti-theft device before I left the store. For the whole day when I was walking through that mall, I must have set off alarms in every store I passed. People kept turning in my direction as I was walking along and I thought, "Is my slip showing?"

Fred Heppner:
Those things ring when you walk in the store, too, right? So you can imagine them all looking at all the people leaving as she is going in, trying to figure out who it is.

Audience Member:
I was shopping in a mall and I had my minivan parked outside. The minivan has one of those alarms in it. I am wandering around the mall and my van's alarm system is blasting all over the place. They were making public announcements in the mall, looking for whoever's car is blasting and, of course, I had no idea what was going on. Finally, I got back to the van and people were standing there trying to figure out what to do.

Audience Member:
I was in the grocery store with a cart full of groceries. I got to the counter, and I was prepared. For grocery shopping, I always try to memorize all the questions ahead of time, like "Paper or plastic?" Usually after that, the cashier asks, "How are you paying?" I usually pay by a credit card. Well, that day I was thinking about other things, and so when she asked the question, "How are you paying," I said, "You have a nice day, too." I went out into the parking lot and I was in a hurry. I was actually pushing my cart and almost running through the parking lot. The store manager ran after me and shouted, "Ma'am, you forgot to pay." I had to go back in the store. The cashier was looking at me like I was crazy.

DOOR STORIES

Cheryl Heppner:
This is one of my dirty little secrets. When there is no one else in the house, I sing. I don't care in what key I am singing or that I am probably slaughtering the song. My hearing dog, Dana, appreciates any kind of singing; and she will never tell. But it happens sometimes that someone will come up to the door while I am singing and I don't realize that they are there.
Audience Member:
A friend had something wrong with the TV in her apartment. She asked a maintenance person to come look at it. The man knew she was a pack rat – she had piles and piles of things all over her apartment. The maintenance man said, “When I come, make a path for me through the apartment.” She thought he said, “When I come, make a pass at me.”

Audience Member:
I had just interviewed for a job, and afterward I decided to go down the staircase because I didn’t know where the elevators were. I started walking, but after a couple of flights, it started getting dark, and I got nervous. Finally I thought I was going to be in pitch black, so I decided to go inside and take the elevator after all. When I tried to get back in from the staircase, the door was locked. I thought, “Oh, my God.” I walked up the next flight and that door was locked. These staircase doors were one-way only doors, and I wasn’t going to be able to get back inside. I couldn’t talk to people on the other side because of my hearing loss, and I didn’t even know which floor I was on. I started pounding on a door, hoping it was not on the floor where I had my interview. It was, but I got the job anyway.

Audience Member:
We have it wired so that when someone comes to the front door, a light flashes five times, and for the back door it stays on eight seconds. Our dog is so conditioned to these lights going on that I just have to trigger the flashing light and he goes to the front door.

Audience Member:
I have lost so much hearing now that I don’t hear the door bell or people knocking on the door. I have my washing machine and my dryer in the kitchen. One day I was in the bedroom in just my underwear. I decided to go in the kitchen and go through clothes from the dryer to decide what I wanted to wear. I get to the kitchen and there is my daughter and her boyfriend. I had not heard them come in.

Fred Heppner:
Obviously, I live through this on a daily basis. It is always a question of what Cheryl is going to do next. Always a barrel of laughs. I look forward to it. Every day is exciting this way for me. She is embarrassed on an hourly basis, of course.

Cheryl Heppner:
You are, too.

Fred Heppner:
But there are lots of laughs involved and we don’t take things seriously. I hope you don’t either.
Hello everyone. I'm your user-friendly cook, Elisa. How many of you want to give better presentations? Well you came to the right place – I hope! We are going to do some cooking this morning, only we are not going to use real food. That sounds weird, heh?

You may be asking, “What does cooking have to do with public speaking in the first place?” Bear with me and it will soon become obvious.

We are going to learn how to get rid of our fear of speaking in front of a group. How to have confidence, and what principles, or spices, to use to give a successful presentation. Sounds ambitious, right? We can do it!

In this paper, I hope to share with you one of my favorite topics, FOOD. It shows. I'm kind of chubby. I enjoy my food.

My husband loves good old fashion Mexican food. His favorite Mexican dish is enchiladas. They come in all sizes and shapes. Sometimes, when I am in a rush, I make him these plain, dry, drabby enchiladas. Trust me, they are still tasty, but they don't look very appealing. On the other hand, when I want to get my husband in a romantic mood, I go the extra mile and prepare him mouth-watering, succulent, spicy enchiladas with all the trimmings.

Now, you might ask, “What is the relationship between cooking and making a presentation?”

A rushed, ill-prepared presentation can turn out to be very boring and unappealing – just like a plain enchilada. You can almost fall asleep. Have you ever been to one of those presentations? Of course!

But an exciting, dynamic presentation is like a delicious, mouth-watering enchilada. You really enjoy it, those times it grabs you. You learn something and it is interesting. Now that's my kind of presentation. With a little help, we can all give those kind of presentations.

What do we have to do is SPICE them up! Let's find out exactly what spices we need to give dynamic and exciting presentations. Let's see how we can SPICE up your presentations.

I am here today to share with you some of the basic principles of public speaking that I've learned these past 9 years in Toastmasters.

I think that you will all agree, that despite being hearing impaired, we like to talk. I have no problem talking; the real problem is that sometimes I can't stop talking! All you have to do is ask my husband!

But, how effective are we at communicating our ideas, especially in front of a group?

Often times, what stops us from becoming effective communicators is FEAR! Yep, it has been proven that the number one fear is SPEAKING IN PUBLIC. I used to think it was death, but
statistically, the number one fear is speaking in front of a group. For most people, panic strikes when they must speak to a group. What are we afraid of: Making a fool of ourselves – forgetting our lines – appearing nervous – embarrassing ourselves.

In order to give a successful presentation, we need to relax, show self-confidence and apply some basic principles.

I always teach that the best way to relax before giving a presentation is to acknowledge that we have a message to give and our audience WANTS to hear it. That’s right; as a speaker you have the privilege of educating, informing and entertaining an audience. When we speak on a subject that is dear to us, that we know very well, it gives us self-confidence and assurance that we will be successful.

If you speak on a subject that you have doubts about, or are uncomfortable with, how on earth, will you be convincing to your audience?

The most effective presentations are those given with conviction, passion, motivation and desire. Once we feel that way, nothing can stop us, NOT EVEN FEAR. If we have knowledge of the subject we are going to talk about, and our audience does not know what we are going to say, it’s a secret until we tell them. So if we lose our lines, WHO CARES! You, as the presenter are the only one that KNOWS that!

A little chemistry demonstration will give us confidence in ourselves and propel us to be great presenters. Think of having two chemistry flasks. One of them, which is full, represents the presenter's brain; and the other, which is empty, represents the audience’s brain.

Now that doesn't mean that the audience doesn't have any brains. It means that they don't have the information that is in this other flask. When I am finished with my presentation, hopefully, all this information in my brain will be in yours. That is how a presentation is successful – information is effectively communicated between the presenter and the audience.

The big problem is that, as you can see, this empty flask has a stopper. When the people come to a presentation they are thinking of a variety of things. Maybe, “I wonder what we are having for lunch?” “I hope this presentation doesn’t take long!” Or, “Maybe I should have gone to the other presentation.” Who knows? You can have a million things on your mind.

It’s the job of the presenter to take off the audience’s stopper, in order to be able to actually pour his or her information into the audience. Now the key to getting the stopper off is to have a breath-taking opening. Something that will get the audience to pay complete attention to the presenter. If you have a weak opening like, “Hi, my name is such and such, and we are going to do such and such,” you have not warmed up your audience. You have not prepared them to listen to you. It is possible you might have even lost that vital contact with your audience before you ever began. If you don’t do something fast, you will lose them for the rest of the presentation.

That first bonding moment with your audience has to be POWERFUL! You have to grab your audience and, of course, later we have to hold their attention throughout the entire presentation. When we prepare, and we must indeed prepare very thoroughly to give a presentation, it is crucial to KNOW YOUR AUDIENCE. The topic we choose has to be relevant and interesting to them and then we have to give them a reason to listen to us.
I always enjoy saying that we have to BRIBE our audience. That doesn't sound very good, does it? But the fact is that the audience must feel that they are getting something worthwhile. Immediately you have to answer their question, "WHAT IS IN IT FOR ME?"

I always grab my audience with a question of some kind. When I walked in earlier wearing with that ridiculous cooking outfit and hat and I asked you the question, "How many of you want to give better presentations?" I got your attention. That is my point – you need to first make your audience realize they should listen to you because you'll give them what they want.

THE KEY TO A SUCCESSFUL PRESENTATION IS GIVING YOUR AUDIENCE WHAT THEY CAME LOOKING FOR!

With this in mind, the basic spices of a powerful speech, are: SALT, PEPPER and MAGIC.

The “SALT” is the contents: information and organization of the presentation. It includes: a very interesting OPENING that grabs and mesmerizes your audience. We tell them immediately, what we are going to teach them. We give them a very basic outline of our speech, backing it up with a BODY of facts, stories, and hopefully, some personal anecdotes.

The body of the presentation must be logical, smooth, and supported by facts and research. Let your audience know why you are qualified and the purpose of your giving such a presentation. This body should be a road-map enhanced with visual aids.

Finally, the CONCLUSION should be properly delivered. It usually calls for action and summarizes your topic effectively. Make a full circle and tell them again what we told them.

The “PEPPER” is the delivery or style of the presentation. It includes:

- **Eye Contact** - It is crucial to establish an invisible bond between presenter and audience. It shows we care. Staring is not recommended but try to “touch” as many people as you can with your eyes. Avoid speaking to the floor or the ceiling. Your audience wants YOUR EYES!

- **Body Language** - A relaxed presenter is one that is casual with his or her body. A successful presenter speaks to the audience as if they were “friends.” No need to worry about, “Where do I put my hands?” Don’t even think about it! Concentrate on your audience, and everything will become both natural and smooth.

- **Vocal Variety** - When we are mad, we shout; when we are angry, we yell; when we are happy, our voice shows it. Your voice must show the emotions involved in your presentation. Avoid a monotone voice. It's boring. The variety of highs and lows make the presentation more interesting.

A major concern for us, being hearing impaired, is that when we give a presentation, the people in the next room tend to also hear us! When we can't hear ourselves, we don't realize that we might be shouting. I had that problem for a long time. I solved it by picking some folks in the front row, who are hearing, to indicate with their hands if my voice is high, low, or ok, and I check with them several times during my presentation. It takes the worry out of that problem.

The third main ingredient is "MAGIC." It includes: visual aids and humor.
In my opinion, this “MAGIC” ingredient makes the difference between a good and an outstanding presentation. We live in a visual world and, in order to bring your presentation alive, you need to make it visual. The audience needs to have mental pictures of what you are speaking about. Visuals help to make your concepts clearer. You have heard that a picture is worth a thousand words, right?

Did you know that 75% of what you have learned has entered your mind visually? Research has shown that we retain only about 10% of what we hear, isn't that surprising!! However, we can remember up to 50% of what we see and hear or up to five times as much. Visuals help us increase retention of what we hear and, of course, when we don't hear, they are EVERYTHING, right?

They help us to retain information, save us time and help to focus your audience's attention. Adding visuals to your presentation adds that extra “MAGIC” to make your presentation outstanding. Your audience will remember your presentation better.

The second part of the magic ingredient is humor. It refreshes the presentation, sometimes takes off the edge of a too serious presentation.

Let's summarize.

1) We need to know our audience and give them what they came for.

2) We have to prepare our presentation with a lot of time and consideration and see ourselves through the audience's eyes and ears, literally putting ourselves in the audience's shoes, and answering that vital question, "What's In It For Me?"

3) The presentation should have a clear opening grabber, a body with facts, stories and a conclusion that wraps it all up.

A final note: PRACTICE, PRACTICE, PRACTICE! The golden Toastmaster rule is practice 1 hour for every minute of presentation time. This was a 75-minute presentation, and yes, I did practice a lot! There is no substitute for practice. Do this at home and time yourself. It is important to speak within the time frame given to you. Speaking longer than requested dishonors your host, your audience and your fellow speakers.

Remember – pick a subject close to your heart and have a BLAST. It's easy to Spice Up Your Presentations, just use SALT, PEPPER, and, of course, a lot of MAGIC.

For more information about Toastmasters International call (949) 858-8255.
SO YOU THINK YOU WANT A HEARING DOG

Cheryl Heppner

WHAT DOES A HEARING DOG DO?

A hearing dog makes contact with its partner and leads the partner to the sound. Among the ways dogs can make contact are touching with a paw, nudging with a nose, or even, for small dogs, jumping into the lap. Some dogs are trained to lead you directly to a sound and others run back and forth from the partner to the sound. An exception to this is in training the dog to respond to the sound of a smoke detector going off. The dog is trained to make contact with its partner, but not lead to the sound because that is where the danger lies. Instead, the dog is taught to make contact and then immediately lie down.

HOW CAN A HEARING DOG HELP?

A hearing dog helps with safety and security and provides companionship, as well as alerting you to sounds.

IS A HEARING DOG RIGHT FOR YOU?

Some things that are important to think about before you decide to get a hearing dog are:

- Do you like dogs, especially dogs in close contact?
- Do you have the space and time to toilet and exercise a dog?
- Do you have a safe place you can leave the dog for short periods, if needed?
- How do you feel about shedding, fleas, cleaning up after dogs?
- How do other people in your household feel about having the dog?
- Do you already rely on other people to alert you to sounds, and are you (or they) prepared and willing to change that relationship?
- Do you already have a dog, and if so, is the dog one who will accept another dog and not interfere with the work of the Hearing Dog, or be adversely affected by the intense bonding with the Hearing Dog?
- Are you prepared for the time the dog needs to adjust to your home?
- Will you be able to adjust your daily routine and put the dog’s needs first?
- Do you have the time and enthusiasm to keep training the dog, knowing that you must continue training and practice as long as you have the dog?
- Can you pay for food, vet bills, etc.?
- Can you handle the public questions and challenges you will face?
WHAT ARE YOUR CHOICES IN GETTING A HEARING DOG?

1. USING A TRAINING PROGRAM

   Among the pros are:
   - Some have experience working with people who are deafened.
   - Some are excellent at selecting dogs and training them.

   Among the cons are:
   - The bond with the dog will take longer to develop.
   - If the program is located far away, you often won't have a local contact to call with questions.

2. SELF-TRAINING

   Among the pros are:
   - Gives a closer bond more quickly.
   - Gives you a source of local support for questions.

   Among the cons are:
   - Risky if you don't have the expertise to select a dog or trainer.
   - Not many trainers are experienced in working with deafened adults.

WHAT SHOULD I LOOK FOR IN TRAINERS AND PROGRAMS?

1. Use of a training method you are comfortable with and that is best for the dog. Some use the positive reinforcement method. Some use the European (choke/correction) method. Some use a combination of both.

2. Assistance Dogs International member, actively learning new techniques.

3. Has a lot of experience and stays on top of new training ideas.

4. Affordability.

5. Your preference about ownership of the dog – some programs retain ownership.

6. Most programs provide certification that the hearing dog is performing effectively with the partner. Some require regular re-certification. The certification process should be strict, but fair.

7. The source of the dog is one you prefer, whether shelter or breeding program.

8. The trainer or program is willing and available to provide follow up with any problems that arise.
This paper is focused on Surviving and Thriving at Work: Developing Skills to Succeed in Job Interviews and to Obtain Workplace Accommodations. It is based on the collective research conducted by researchers from the University of Arkansas Rehabilitation Research and Training Center for Persons who are Deaf or Hard of Hearing, where I serve as Director of Research. The paper covers three different areas. It initially presents an introduction to our Research and Training Center. Second, it discusses research related to job seeking, especially in the area of job interviewing. Finally, it introduces information about problems faced when trying to obtain job accommodations.

THE UNIVERSITY OF ARKANSAS RRTC

The University of Arkansas Rehabilitation Research and Training Center for Persons who are Deaf or Hard of Hearing is funded by the National Institute on Disability and Rehabilitation Research (NIDRR). NIDRR funds over 40 centers around the country that focus on the rehabilitation of different groups of people with disabilities. We are the older of two centers that focus on the needs of people with hearing loss, including those who are Deaf, hard of hearing or late-deafened. The second Center is located at the California School of Professional Psychology in San Diego, California.

Our Center, which is in Little Rock, Arkansas, has been at the University of Arkansas for 17 years. Over that time, we have conducted many research, training, and materials development projects. This paper is primarily focused on recent research that is relevant to the needs of late-deafened or hard of hearing consumers.

Initiated six years ago, this research has continued during our current funding because of the many issues that were identified in surveys of the workplace experiences and needs of the hearing impaired. Many of you may have been involved in the survey research that led to the materials plan to discuss today. The surveys asked ALDAns, and other persons who were deaf or hard of hearing about the problems, barriers, and successes they have had in the workplace. Let me thank those of you who participated in these studies.

The mission of our Center is to conduct research related to all aspects of employment, including preparing yourself for jobs, getting jobs, accommodating yourself in jobs, and succeeding in jobs. We have been charged by NIDRR to work with the full range of persons who have hearing loss. We have had many years experience in working with folks who are culturally deaf. More recently, we have focused heavily on persons who are late-deafened or hard of hearing. Much of this work has focused on working with organizations like the Association of Late-deafened Adults and Self Help for Hard of Hearing Persons. Finally, we have also focused on working with persons described as low functioning deaf—those who have multiple disabilities, one of which happens to be hearing loss. These persons face a whole constellation of problems, and thus, could benefit from significant
rehabilitation services. We have also been heavily involved in looking at issues related to people from diverse racial and ethnic minority groups.

There are five primary research projects funded under our base grant.

1. **Pathways and Barriers to Workplace Success** is a descriptive project. We have been asked to help develop a body of information that describes the socio-demographic characteristics, service needs, and rehabilitation outcomes of the full range of people who have hearing loss. There has not been a census of deaf persons in many years, and there has never been a national census of late-deafened or hard of hearing persons. This lack of data limits our ability to obtain needed support for services at the federal level and the information needed to improve services.

2. **School to Work Initiatives** focuses on programs designed to partner educators with employers to enhance career preparation and transition to work. Students get the opportunities to learn and apply their classroom knowledge in the real world. This project will identify the effective components of model programs.

3. **Rehabilitation Interventions** continues to collect information to evaluate and validate the outcomes of skills training interventions. The Center has developed a number of these interventions throughout the years that are being further evaluated. Today's presentation will highlight two of these interventions – one for job interviewing and a second on job accommodations.

4. **Employer Perspectives** is a project focused on the expectations of employers and the service provider resources available to employers that desire to work with employees with hearing loss. You have to assume that employers want to hire people who will become good, productive employees, and would be willing to hire workers with hearing loss. The project will identify the needs of employers who are working with these persons, as well as how we can help employers meet the needs of these workers.

5. **Remote Access Technologies for Communication** explores harnessing new technologies to give persons more communication access. Internet-based communication, remote CART, and applications of video conferencing in interpreting are alternatives being explored.

In addition to these research projects, we have many training activities and materials development activities. The cornerstone of our training efforts is graduate education leading to master's degrees in rehabilitation counseling or independent living counseling specializing in working with the deaf, late-deafened or hard of hearing. If you are looking for a career, or desire to change to a new career in this speciality, please feel free to contact us. We have federal support available to qualified students while they complete the 2-year program.

**RESEARCH INTO JOB INTERVIEWING**

As a research group, we have conducted a number of studies to identify needs, develop materials or resources directed toward these needs, and then validate the usefulness of these materials in producing enhanced employment outcomes. Often presentations from researchers focus heavily on data resulting from their studies. Rather than present the statistical results of these different studies, I would prefer to just state that the materials I plan to demonstrate have been well validated.
Two separate lines of research identified the need to develop materials that will help persons prepare to succeed in the job interview. Two key guidelines were used to develop materials. First, the materials were designed to focus on problems experienced by persons who were late deafened or hard of hearing in the interview. Second, the information and content was presented in accessible formats. For example, if you are designing materials for people who use sign language, they should be relevant to the problems experienced by sign language users. They should be in sign language to ensure accessibility. If you are developing materials for people who are hard of hearing or late-deafened you want the materials to be captioned for accessibility. They should also depict models of people who are late-deafened or hard of hearing actually demonstrating these skills. The resources that we have developed follow these guidelines.

Many job seekers have the training and skills they need to succeed in the workplace. Yet, we know that unemployment of persons who are deaf or hard of hearing is higher than the hearing population. At least one reason for this situation is that deaf or hard of hearing persons have difficulty in marketing themselves in job interviews. Almost all job seekers must demonstrate their ability to sell themselves in a interview prior to obtaining a job. Much research has gone into trying to identify how to succeed in the interview and to develop resources for persons who desire to learn these skills.

Most people experience a variety of problems in job interviews. For some, these problems are “interview nerves,” due to uncertainty about the interview process and how to respond to questions asked by the interviewer. Still others describe lousy experiences due to the simple fact that the interviewer was not very skilled and was unprepared.

Others may be concerned about communication issues that stem from hearing loss. Many interviewers have never really met or interviewed a late-deafened person. They are unsure about what to say and how to ask questions in an appropriate, non-offensive manner. They may not have a clue about how to accommodate communication.

Regardless of the reason, it is your responsibility to present yourself in the interview – to sell yourself and be sure that the interviewer understands that you are uniquely qualified for the specific job. Many persons have told me that their hearing loss clearly impacts their ability to succeed in interviews. In fact, when asked to rate impact on a 1 to 5 scale where 5 is a great deal of impact, the average rating was around 4. We set about trying to develop a package that would help persons deal with these problems.

Originally, we developed a package called: Getting Employment Through Interview Training (Johnson & Boone, 1990). This video-based curriculum was designed for sign language users. It was based on materials developed for job seekers with a variety of disabilities by another research group. The curriculum taught job seekers about the different parts of the job interview and the skills needed to succeed in the interview. It consisted of a trainer's manual, a learner's workbook, and a series of lessons presented in sign language on videotape.

Clearly, this sign language based package wasn't designed for all users who have hearing loss. People who don't sign would obviously have difficulty understanding the materials, and probably would not identify with the models depicted on the tape. Persons who are late-deafened or hard of hearing told us they needed materials that were relevant to their needs and accessible from a communication standpoint. Therefore, we developed a new version of the training resource, GET-IT: An Interview Training Resource for Job Applicants with Hearing Loss (Boone, 1999). This curriculum includes three primary components: a manual, a closed captioned videotape, and a number of worksheets to help learners during the training.
Each GET IT lesson includes three primary structures. First, a narrator describes the kinds of skills that employers expect job applicants to show in interviews. Second, these skills are illustrated or modeled by people who are late-deafened or hard of hearing. Some of the interviewees are highly skilled, others are not. Thus, persons get to observe multiple models of people implementing the kinds of skills that employers expect. This variability is important to the learning process. There is no single, perfect right or wrong way. To succeed in an interview, applicants have to present themselves in the best possible light that is personally comfortable, and also impresses the employer. Each applicant should interview using their own unique style. But applicants should keep in mind the kinds of behaviors and the kinds of answers that interviewers are looking for. Finally, the lesson gives guidelines for practicing the skills through the use of role playing.

The GET IT curriculum really includes nine lessons. These lessons correspond to the distinct parts of job interviews. The lessons include:

- Orientation to the Interview
- Greeting the Person at the Front Desk
- Greeting the Employer for the First Time
- Answering Questions Confidently
- Asking for Important Questions
- Offering Information
- Closing the Interview
- What if You are Not Asked
- The Complete Interview

Eight to ten learning points are covered in each lesson. Let me briefly describe some of the learning points included in the materials. In the introductory lesson, narration covers how to initiate the interview process, starting with the first contact with the company. Prior to the actual interview, one must conduct an analysis of his or her skills and match them to the duties of the specific job. This information is used in the first contact with the company. Usually this contact is written, consisting of a cover letter and a vita or resume that describes the applicant. The sole purpose of these written documents is to describe oneself in such a way that the applicant will be asked to interview. If one succeeds in this step, he or she will probably have to meet for a face-to-face interview. Dress, punctuality, and knowledge about oneself and the job via preparation are related to a successful presentation in the interview.

When applicants actually go to the interview, they will typically first meet a person at the front desk. This person may not always be a receptionist, they may be the boss. So you must assume that the interview has started when you walk in the door to the company. Even if the first person you meet is not the interviewer, he or she may subtly influence the interviewers opinion of you in the way they introduce or contact the interviewer.

At the start of the interview, you must be prepared to demonstrate how you will communicate at work, by taking control and managing the communication situation. For example, if you must rearrange the physical situation to facilitate communication, be prepared to explain your need and request the needed change. If you use a technological accommodation like an assistive listening device, be prepared to describe its use for the interviewer. If you require the accommodation of a CART reporter or an interpreter, set the stage for the interviewer and describe how this service provider will be of benefit to both of you. The bottom line is employers want to hire good workers that they can work with. Much of this relationship depends upon your ability to communicate, so you must clearly demonstrate how the two of you will communicate. If you can't accomplish this goal,
it will be hard for the interviewer to form an accurate impression of you and your abilities. If asked, be willing to describe the ramifications of your hearing loss at work.

Much of the job interview will be spent answering questions posed by the interviewer. Respond confidently and stick to the point. If you are unsure about questions, restate them. Be sure your answers emphasize your strong points in terms of your skills, abilities, and training to do the job. Even questions about your personal interests and hobbies should clearly relate to the job.

At some point in the interview, you should be prepared to ask questions about the job. Be sure and focus your questions on the job and the work environment. Hold specific questions about pay, benefits, and promotional opportunities until you have asked questions that demonstrate your interest in the job and its duties.

I hope these examples give you an understanding of the range of content that is included in a job interview. Obviously there is more information in the resource than I've covered. At the end of the presentation, I will give you information regarding how to obtain the full GET-IT resource.

RESEARCH INTO OBTAINING JOB ACCOMMODATIONS

A second line of research conducted by our Center found that many workers who had recently experienced hearing loss were unsure about how to identify and request appropriate communication accommodations. Furthermore, surveys of the employers of these workers also found an overall lack of knowledge about accommodations as well. These two findings resulted in the development of a Job Accommodations Curriculum (Sherich & Berkay, 1996), which attempted to meet this need. This text-based resource was presented to workers who were hard of hearing or late-deafened. While the resource was viewed as useful, most of these individuals felt the curriculum could be substantially improved through inclusion of multimedia demonstrations of accommodations, images, graphics, and where possible, videos of people using various accommodations. Toward this goal, we successfully applied for, and were awarded, a knowledge and dissemination grant from the National Institute on Disability and Rehabilitation Research.

This three-year project is designed to harness multimedia computer-based technology to produce this curriculum. Currently in its second year, the project has started producing: AcCOMModate: Communication Accommodations at Work. Presented using a simulated teleconference, the AcCOMModate resource will cover four primary topics:

1. Defining Accommodations
2. Identifying Your Accommodation Needs
3. Choosing An Accommodation
4. Marketing Your Request.

Let me provide you with examples of the content in these topic areas. Defining Accommodations is designed to overview the concept of accommodation. It defines and gives examples of four key categories of accommodations: equipment, support personnel, job restructuring, and workplace modifications. This information is presented by an on-screen “live” narrator who provides narration to illustrate the content seen on a teleconference screen. Figure 1 illustrates what users would see on the computer screen.

The second topic, Identifying Your Accommodation Needs, presents users with eight categories of workplace situations. The situations include: receiving instructions/talking with your supervisor, performance evaluations, department meetings, in-service training, work-related social functions,
socializing with co-workers, working with customers or the general public, and alerting devices. Users are provided the opportunity to assess their need for accommodation in each situation by answering questions about potential problems experienced in each situation. Answers to these questions lead to the development of a list of potential accommodations that may assist the individual. Figure 2 illustrates the format used for this topic.

The third topic, Choosing a Preferred Accommodation, is designed to introduce users to problem solving skills. These skills are designed to help users narrow the list of potential accommodations to specific accommodations that best fit the workers situation.

The final lesson, Marketing Your Request, provides guidelines and examples of effective ways to approach employers with an accommodation request. The resource also includes a multimedia glossary that may be accessed at any time to obtain more information or an explanation of a specific accommodation.

We sincerely hope that this will be an engaging strategy to provide persons with the information they need to make informed assessment and negotiate for workplace accommodations. When available, we hope it will be a fun way to obtain information of benefit to users.

Conclusions

Let me conclude by thanking you for your interest in these materials and this presentation. Your participation in different aspects of these projects continues to drive these projects toward the development of materials that are of use to you. For more information, about our Center or specific projects and products, I would like to encourage you to contact us using any of the strategies listed in Figure 3 which is a copy of our home page from the World Wide Web. Once again, thank you for inviting our Center to present at ALDAcon. We look forward to continue working together to assist persons with hearing loss in their efforts to succeed at work.

References


Figure 2

Each question has a visual, spoken, and textual representation.

Clicking on the response buttons will branch to the next question.

Is the lighting in the room poor?

Lists current topic

Topics buttons

Select one of eight common work situations to identify communication problems

Repeat previous question

Progress bar indicates position in question list

Shows function of button when cursor is positioned over button

Quit program and return to desktop

Go to agenda or main menu (highlighted version)

Go to multimedia glossary

Display textual and video help information

Print button becomes active when needed
Visit our Website:
www.uark.edu/depts/rehabres
INTRODUCTION

In a panel discussion with a target audience of service providers, six successful deafened professionals shared their experiences and struggles to "make it" in the working world as deafened adults. In addition they talked of the ways that vocational rehabilitation and other service providers either helped or hindered the process. Panelists then provided their recommendations for improved consumer/service provider partnerships. The panel discussion ended with a lively question and answer period.

PERSONAL AND WORK HISTORY

Recognizing how far the panelists had come, both professionally and personally in terms of increased confidence and assertiveness, one panelist stated,

Right here [on the panel] you see six kick-ass advocates... who probably at one time or another in the past, were six wet noodles who were very vulnerable. Now I have a job where I can use my advocacy skills, assistive technology skills, my computer skills, all wrapped into one, and it is cool. But to get here...

Another panelist, who became hard of hearing in high school and later lost her hearing completely due to Meniere's Disease, shared her story of a career dream. She also spoke of her frustration in encountering attitudinal and communication barriers both as a hard of hearing nursing student, and, later, as a late-deafened nurse. She had this to say,

Ever since I was a little girl, I have always wanted to be a nurse. Now I am realizing that dream, but it was a long road in trying to achieve that goal - this was in the 1970's where we didn't have the ADA law - and I didn't know anything about sign language. There was also no such thing as CART.

This woman was advised by nursing school admissions offices to not pursue RN training/certification due to her hearing loss. Instead, she completed her LPN training and worked for a number of years in a hospital as an LPN. Recounting her story, she said:

Fifteen years later, I became completely deaf with Meniere's... I wanted to go back to work... [and I was told] I'm so sorry, we don't have a job for you, but we will pay you disability.' I told them, 'but I am not disabled. I just can't hear. I don't want disability.' After that I became depressed.

After several years of working in medical records, however, she regained her professional self-confidence and returned to nursing as a career. Currently, she serves as director of residential and health services at her facility, and is pursuing her BSN degree part-time!
Several other panelists talked about the emotional impact of discrimination and low expectations of employers, and potential employers. One panelist stated, "There is so much pain involved...the door is closed in your face. You hear 'no' a lot. It affects you emotionally." Another added, "I could not talk with people without an interpreter or CART, so my dream went down about seven notches."

Another panelist shared his experience of using Vocational Rehabilitation (VR) services for the first time. He noted that the loss of independence in becoming a "client" can be difficult for some to reconcile, "Society teaches you to do it yourself. Now, you have to ask for something."

After overcoming his initial apprehension of using VR services, the panelist encountered low expectations from his counselor. "I told them that I wanted to become a computer programmer, and they suggested that I become a paralegal!"

This panelist continued to seek VR support for computer training and, in the process, encountered governmental red tape and bureaucracy. He became an expert on federal and state VR guidelines and rules, and learned the art and science of individual advocacy in the process, which resulted in his finally receiving the support for the specialized training he wanted.

Another panelist noted, "I think that we need to figure out a way for VR counselors to be able to both do their jobs and keep their jobs as VR counselors by making their bosses happy. At the same time, consumers must be allowed to pursue their highest goals instead of 'we will get you a printing job or a paralegal job'."

Other panelists shared more positive experiences with the VR system and their VR counselors. One shared, "I was supported by the VR services in order to obtain my master's degree in deaf education." Another panelist mentioned that, although she had never been an actual client in the VR system, she did experience positive feedback and encouragement in job advancement and career aims through informal consults with the VR personnel in her area.

Most of the panelists had been in contact with VR services during the 1970's or 1980's, in the days before the Americans with Disabilities Act (ADA). Certainly, the focus of VR has changed with the advent of Title I of the ADA and the expectation that employers and potential employers will make the necessary "reasonable accommodations" needed by their employees. All the panelists noted how empowering the ADA had been for them in advancing in their careers.

**COMMUNICATION WITH SERVICE PROVIDERS**

The panelists discussed the ways that they communicated both with VR counselors and on the job. Panelists mentioned signing, writing back and forth, CART (less often, but growing), and speech reading. One panelist noted that VR counselors sometimes make the mistake of assuming that communication is easier for the deafened consumer than it really is and do not offer alternatives. This panelist advised service providers to, "...ask the consumer, 'What do you need? What do you want for communication in the office'."

Another panelist noted that her VR counselors would, "Frequently sign to me when they spoke to me, some of them all the time. That communicated to me that this was another way to communicate. I really appreciate that."

Several consumers added sign language to their repertoire of communication options. One panelist shared, "The very first time I even saw sign language was with my VR counselor...VR gave me
a lot of access and helped me to begin with sign language." With sign language, the panelist was able to become a consumer of interpreter services.

Another panelist, who utilized VR services during the 1970's when he was a young undergraduate student, had this to say,

I don't know if my lip-reading ability, which I can tell you proudly is very, very, very good, was a benefit or a hindrance to what I did through the [VR] system. Maybe because I read lips so well, they assumed I would be fine without an interpreter. They never offered one. But I really didn't know what the hell was going on in classrooms without an interpreter.

In speaking of on-the-job communication, another panelist told of having interpreters. "All I would have to do is send an e-mail request [for one]."

Employers in both the private and public sectors are becoming increasingly sophisticated in providing interpreters and CART reporters as "reasonable accommodations" for their deaf and hard of hearing employers. At the same time, new technologies such as e-mail and the Internet are emerging as valuable tools in equalizing communication for deaf employees.

**RECOMMENDATIONS TO SERVICE PROVIDERS AND CONSUMERS**

Service providers and consumers were encouraged to think outside of the box and "be creative" in developing career and training plans and goals within the VR system. One panelist reminded the audience that often with deafened consumers, other issues are happening at the same time; such as anger and all the other things that go along with the grieving process. Service providers must take these psycho-social issues into account and meet the consumer where he/she is in the grieving/adjustment process.

Several panelists emphasized the importance of service providers to refrain from generalizing or labeling their deafened consumers – they need to remember that what works for one consumer, may not work for another. As one person commented, "Don't put consumers in a box and compartmentalize them."

To understand where a deafened consumer is coming from and what he/she needs, it is crucial to listen to what they have to say about their hopes, dreams, and goals. As a panelist stated, "I think we all know that listening on all levels is very important – not just to what is said, but also the body language."

Every deafened consumer needs information about communication options, available technology, services, resources, etc. One panelist noted, "[The newly deafened consumer] is vulnerable and knows nothing about technology, about other means of communication. They need information." "But," the same panelist cautioned, "information-overload can drive a consumer away, and it is necessary to walk a fine line in terms of offering information without scaring newly deafened people away."

Another panelist mentioned the recent reauthorization of the Rehabilitation Act in 1998 and encouraged service providers in attendance to learn more about the new consumer-focus of the reauthorized Act. The 1998 amendments emphasize, "More consumer choice... and collaboration and partnerships with the consumer."
In reference to his own experience with VR and the low expectations he encountered when presenting his career goals, one panelist noted that, "Instead of offering [consumers] the moon and seeing what they can come up with, they are getting offered the bottom line. They [VR service providers] are thinking of cost." The panelist who is now realizing her dream of obtaining her RN added, "I wish I had in the 1970's asked for the moon... but I know now in the 1990's that I can ask exactly for that and advocate for myself."

Aptly summarizing the discussion, a last panelist echoed the sentiment, "If you are a consumer of VR, ask for the moon. If you are a VR provider of services, please try to help your clients reach their highest potential. Most of us won't ask for the moon. But it is a wonderful opportunity to be able to have the tools to try to go for it."
MANAGING YOUR HEARING BOSS

David Baldridge and Carol Menton

BACKGROUND

People who are deaf or hard of hearing face many workplace challenges; and, there is a need to identify the best ways to overcome these obstacles. While no one has all the answers, we need to share with one another in hopes of not only identifying common problems, but finding good solutions.

While the title of our workshop was Managing Your Hearing Boss, due to the fact that our supervisors play a pivotal role in our work lives, a more complete title might be Managing Your Work Environment. This would, thus, acknowledge that we must also deal with co-workers, subordinates, and customers in such a way as to shape their work environment so that it becomes more hospitable to ourselves and others who may also have a significant hearing impairment. Examples include: improved lighting, making requests for TTY’s, or simply asking co-workers to slow down when they speak. In each of these cases, the employee who is deaf or hard of hearing takes action to improve his or her work environment.

When the Americans with Disability Act of 1990 (ADA) became law, it was hoped that this legislation would dramatically improve the employment opportunities of people with disabilities. Unfortunately, this has not been the case. Studies show that employment levels for people with disabilities have either remained the same, or worsened since enactment of the ADA. Many legal scholars have concluded that the ADA, as it is currently written, is ineffective.

While it is clearly critical for ALDA members to continue to advocate their rights under the ADA lest we lose ground we have gained, it is also important to go beyond self-advocacy. By self-advocacy we mean relatively straightforward requests for accommodation that rely on the legal power of the ADA. For example, demanding a TTY, or interpretation for all meetings, and perhaps giving your boss an ADA attorney’s business card.

Such requests, however, often build resentment among supervisors and co-workers, and may do more harm than good.

In contrast, management of our workplace environments involves looking at the big picture, using more sophisticated strategies, and trying to find the best solutions for everyone involved. For example, consider the following comment from a participant in our session, “I called (my boss) via the Relay Service and he didn't like the Relay, but he said, ‘How about a chat room (on the Internet)?’ We went into a chat room and it worked beautifully. From then on, he began paging me, saying, ‘Let's meet in a chat room.’”

Had this gentleman persistently demanded that his boss use a TTY, the boss might well have become very resentful. By focusing on the big picture, however, it was possible to not only improve his work environment, but bring his boss closer rather than alienate him. This was very skillful management!
In our session, we identified three key components of successful work environment management: knowledge, advocacy, and interpersonal savvy. Employees need to be knowledgeable about their rights, potential aids, job requirements, and realize what changes might be helpful. Advocacy requires self-esteem and assertiveness, and the ability to take action. Finally, interpersonal savvy requires knowledge of others' needs and negotiation skills.

To learn how to be skillful managers, we need to share problems as well as solutions. Here are some of the actual experiences that our workshop participants have had to deal with.

- Asking for an interpreter and being told that they do not want interpreters standing there, while the use of foreign translators for foreign languages is common.
- Calling a meeting to explain about your needs due to your deafness and then being cut off in the middle of it.
- Having to ask for a TTY as an accommodation in your work.
- Being involved in a meeting where the interpreter was very late and you were embarrassed.
- Having to change not only your job, but your career because of your deafness.
- Having to think about how easy it would be to use the telephone if you didn't have deafness or hard of hearing issues to deal with.
- Being unwilling, or unable, to go to office parties because your interpreter was only paid to be there for the 8 hours you work.
- Being in a meeting where a suggestion is made and everybody turns around and looks at you as the whole meeting comes to a standstill.
- Being told by your boss not to ask someone to repeat himself or herself to avoid embarrassment.
- Pretending to understand what a co-worker said.
- Having a boss look at the paper when you were talking to her or him.
- Having to watch an interpreter, a handout, and an overhead all at once.
- Having something good happen at work because you're deaf: a special opportunity or something special happening.
- Having conflicts with your co-workers or students and then being convinced that the boss is taking the side of the hearing person.
- Having mornings where you just can't get yourself out of bed because you know that your boss will humiliate you at work.
- Having a boss that didn't have enough consideration to face you when you were trying to talk to him.
Managing Your Hearing Boss

• Being in a position of wanting to participate in office politics, but not being able to hear conversations taking place in dark taverns.

• Having your boss come up and whisper in your hearing aid during a meeting.

IDENTIFYING PROBLEMS

• In dealing with these events, it helps to know common and significant problems that may be faced in the workplace.

• Missing out on small talk and office gossip.

• Last-minute events and not being invited to last-minute events because of lack of communication access.

• Understanding people with strong accents.

• Not being able to follow multi-communication – for example, watching the interpreter, looking at handouts, and watching overheads all at once.

• Being the last one to know.

• Co-workers thinking that your interpreter or CART reporter is your helper.

• Expectations that you will understand everything when an interpreter is present.

• Being deprived of training experiences because money for CART or interpreters was not available.

• Other people insisting upon the most difficult way to communicate with you – for example, through voice messages rather than e-mail or TTY’s.

• Lack of cooperation from co-workers, such as an unwillingness to even try to communicate.

• Unrealistic expectations, humiliation, and oppression.

SOLUTIONS & BEST PRACTICES

Once problems are identified, some general guidelines for problem solving can be formulated. Using some of the following positive management strategies may be of help.

☆ Planning in advance for meetings, and negotiating a room that has good lighting and acoustic characteristics.

☆ Asking for an interpreter.

☆ Asking that last minute meetings be rescheduled, or requesting that someone take notes if the meeting cannot be rescheduled. Using a TTY or computer for notetaking can be helpful too.
• Being appreciative of the efforts that others make. As one workshop participant said, “We need to be very specific again and again and again about what we need, and not take it personally that we don't always get it. I really think my boss and my co-workers are trying. I think they forget. They often don't realize that I need to sit in certain positions because of the light. And so forth, on and on. I think we need to be clear and then not take it personally when we have to keep reminding them.”

• Using positive reinforcement. Most of the time people are willing to help, if they can and if they remember. They have a lot of things to think about besides just our being happy. For these meetings, sometimes if you ask whomever is running it to print out and make copies of the paperwork for you and make sure you get them maybe an hour ahead of time, it helps a lot.

• Initiating communication: What is helpful is not to expect people to call you, but to call them and to initiate the conversation or initiate the contact with them. Once you get them on the phone or start the e-mail conversations, they will feel free to communicate with you. But if you rely on them to start the communication, a lot of times it doesn't happen.
This panel presentation focused on a discussion of ways and means by which states might enhance rehabilitation and employment services and outcomes for adults who are late-deafened. It was moderated by Dr. Douglas Watson of the University of Arkansas Rehabilitation Research & Training Center for Persons who are Deaf or Hard of Hearing (RT-31). The panel included State Vocational Rehabilitation Coordinators for the Deaf (SCDs) from RSA Region V (states such as Illinois, Minnesota, and Ohio). It also included one Rehabilitation Counselor for the Deaf (RCD) from the Chicago area who had a mixed caseload of deaf, late-deafened, and hard of hearing consumers. A representative of the Deafness and Communicative Disorders Branch in the Rehabilitation Services Administration (RSA) and the Federal Office of Special Education and Rehaabilitative Services (OSERS) in Washington, D.C. also served on the panel.

The goal of the panel was to provide an opportunity for state VR program managers in the midwest region to interact and share with ALDA members their perspectives on current and future priorities for state VR employment and rehabilitation services for late-deafened and hard of hearing persons. There were a number of exciting VR service delivery issues addressed by the panel.

Historically, the primary focus in this nation’s deafness rehabilitation service delivery system has been directed to serving those deaf individuals who lost their hearing early in life and had been educated in special classes and schools for students who are deaf or hard of hearing. More recently, however, public and private rehabilitation programs have begun to redefine and otherwise rethink the populations targeted for services in this country. State VR agencies are beginning to recognize there are segments of the hearing-impaired population that merit special focus and effort, namely persons who are late-deafened and hard of hearing.

Specifically, there is a need for public and private rehabilitation programs to respond to the unique communication problems that these people bring with them to rehabilitation. This would, for example, particularly affect people with adult onset hearing loss of varying degrees of severity. The panel addressed these problems, focusing on state VR efforts to improve rehabilitation efforts on behalf of late-deafened individuals.

Following a brief statement from each panelist, participants were invited to interact with the panelists in a question and answer format regarding initiatives in VR services for persons with adult onset deafness. The goal was to stimulate a dialogue between ALDA members and representatives from the Federal/State Vocational Rehabilitation Program. To start with, George Kosovich, who is with the federal office of the Rehabilitation Services Administration (RSA), shared some thoughts and perspective from our federal partner.
George Kosovich:

Let me tell you a bit about my personal background. I am a former VR client and worked as a VR counselor for 12 years in Oregon before I moved to Washington D.C. In 1990, I went to work for the Deafness and Communication Disorder branch within RSA as a VR program specialist, serving hard of hearing and late-deafened individuals. I have been there since 1990; and it's been an experience.

The focus of my responsibilities is to improve rehabilitation services for hard of hearing and late-deafened individuals. This focus came about as it was realized that most of the attention had been previously placed on the needs of individuals with early onset hearing loss, primarily Deaf individuals. Rocky Stone, a founder and executive director of Self Help for the Hard of Hearing, Inc. (SHHH), pointed out that RSA needed an advocate for hard of hearing and late-deafened people. In response, RSA appointed me to one of their personnel slots.

I have been trying to get the job done. While I don't feel that we have made the progress I'd like to see, we have made progress and continue to fight for more. The battle being, basically, that we just don't have enough trained staff out there to address the needs of the hard of hearing and late-deafened.

We are training more and more Rehabilitation Counselors for the Deaf (RCDs), and that's good. RCDs are trained primarily to work with individuals who are deaf. Within the federal Office of Special Education and Rehabilitative Services (OSERS), we have funded 14 long-term training programs as well as rehabilitation counselors for the deaf. I think about 8 to 10 of these are graduate degree training programs. The others are orientation-like programs, such as introduction to deafness or other short in-service training programs.

I think it is great that we have more trained RCDs out there. Most RCDs have been trained primarily to work with deaf individuals. Basically they must have some level of sign language skills in order to be proficient enough to communicate with deaf clients.

Unfortunately, I don't think that – in terms of numbers – they're able to meet the demand for services that exist.

Consequently, I think that general VR counselors need to be trained to work with hard of hearing and late-deafened individuals. As long as general VR counselors don't have to learn sign language, it really reduces the time required for training. I think you can train a general counselor to serve hard of hearing and late-deafened persons within a month. We need to develop a full curriculum suitable for training experienced rehabilitation counselors. If done correctly, such training would permit us to more effectively address communication access needs of hard of hearing and late-deafened individuals, as well as allow us to effectively counsel clients and work with them towards rehabilitation and job placement.

Current resources in place could include Doug Watson's program at the University of Arkansas Rehabilitation Research and Training Center for Persons who are Deaf or Hard of Hearing, plus the Research and Training Center at California School of Professional Psychology which is focused on Employment of Individuals who are Late-Deafened and Hard of Hearing. We also have a Rehabilitation Engineering and Research Center which has been operated by the Lexington Center in New York City. Those three research centers are funded by the National Institute for Disability and Rehabilitation Research (NIDRR),
which is the sister or brother organization to the Rehabilitation Services Administration (RSA) within OSERS.

RSA itself operates a number of short and long-term training programs. But, I have some concerns as to where we are with training personnel to serve hard of hearing and late-deafened individuals.

RSA also funds Interpreter Training Programs (ITP). This funding totals approximately $2.1 million a year during the present funding cycle, supporting 10 regional and two national ITP programs. Their mandate is to train interpreters: sign language interpreters, oral interpreters, cued speech translators, and deaf-blind interpreters.

Some of us at OSERS were hoping to see that mandate broadened. We wanted to make changes in the legislation language where it talks about training interpreters for individuals who are deaf. As it developed, that language didn’t get changed. The field still needs to find a way to get funds put aside for training Computer-Aided Realtime Translation (CART) providers or other kinds of communication facilitation services. We’re working on that. If you have any ideas, please let us know how we can go about getting funding for necessary and important services such as CART.

As I said, we need trained staff who know how to address all these needs. I really think that is the primary focus right now; finding a system for training counselors beyond the RCDs. The RCDs are a good way to go. We’re training more counselors to work with the full spectrum of the population of people who have hearing losses, but it’s a slow process.

I don’t know how many people graduate a year in those RCD training programs. I would guess that probably 5 to 10 people get graduate degrees from each of the 10 RCD training centers each year. But we need many more.

Also, according to the information I have, not very many states have full time State Coordinators for the Deaf (SCDs). RSA really needs to communicate better, so we need to build a network that would allow all of us to know what’s going on around the country. I believe RSA could serve as a hub for that network in terms of making the communication network flow and taking a look at needs so gaps can be filled in.

Douglas Watson:
Our second panelist is Skip Berquist, State Coordinator (SCD) of VR Services for Persons who are Deaf or Hard of Hearing in the state of Ohio.

Skip Berquist:
I want to give you a little bit of an overview on what’s happening in Ohio. Currently, we have 19 Rehabilitation Counselors for the Deaf (RCDs) in the state of Ohio who have already met the minimal communication sign competency requirement. We also have 10 other counselors who carry general caseloads, but also serve deaf and hard of hearing clients. Those 10 persons don’t really have significant sign language skills. Most of them live and work in rural areas. This system is very helpful for us because many of our RCDs don’t want to live and work in the rural areas because they are not attracted to living in rural areas.

Ohio is one of the states that provide for a bilingual pay scale. People who qualify are given a 5% increase once they have met the language requirement. Also, annually, we have a statewide meeting for all the RCDs who are deaf themselves; and we provide them with
specialized training. We focus on things like training the RCDs to serve people who are hard of hearing. Part of that training has focused on how to deal with hearing loss.

Even so, I have to admit, we don't have much information about late-deafened individuals; and we lack good training curricula materials. But, we're still trying our best to give counselors some supplemental training in working with people who are late-deafened so they can be more effective.

We are also trying to expand our service to other populations who have a hearing loss, and not focus our efforts only on serving "culturally Deaf" individuals. Please keep in mind and understand that VR is not an entitlement program. It's based on eligibility. Also, VR does not really focus on the disability itself, but instead focuses on the limitations the person has due to their disability.

In effect, VR has to look for various limitations in areas such as mobility, communication, daily life, and career goals. A person's independent living skills and abilities, as well as related criteria, are also considered in the VR eligibility process.

In reality, a person could be fully deaf, maybe have a college degree, and not be eligible for VR services. Or you may have someone who has a hearing loss, perhaps is late-deafened, who would be eligible. It really depends on the specific individual.

Ohio does have "an order of selection." We have targeted, and give priority to serving, those individuals who have the more severe disabilities. That's our primary "order of selection" policy. Once we have served the more severely disabled client group, then we can and will serve those who are not as severely disabled, if resources permit.

That is the reason we consider the individual's total situation in life and work, and not the disability itself. We would encourage each of you to become involved with your home state public and private rehabilitation agencies and become part of the state VR advisory council. The rehabilitation community really does need to hear from you. We also need to hear from you about how you believe we can develop better rehabilitation services and programs in the areas where you live and work.

We encourage you to become involved with your public and private rehabilitation agencies and counselors: make recommendations and bring up issues. By getting involved, you may be able to influence the establishment of some innovative programs or services in the community that addresses the needs of late-deafened individuals. Your involvement may assist the rehabilitation community with identifying and implementing programs and services that are more responsive to the needs of the late-deafened.

Let me give you an example. Our state agency regularly provides consumer workshops, leadership training, transitional programs, and workshops for kids. We also provide assistance for those who are getting ready to enter the workplace and life after high school. We have established advocacy groups, including training opportunities, to assist or help our consumers achieve successful school-to-work transitions. We also have co-sponsored several workshops with the ALDA association, with various Ohio SHHH groups, other disabled consumer advocacy groups, interpreter groups, and deaf-blind consumer organizations.
So, there are many ways that you can become involved. Let your concerns become known. We encourage you to work with allied consumer advocacy groups and key public and private rehabilitation agencies.

**Douglas Watson:**

We have heard from two panelists from eastern states. Now we move to the midwest and introduce the State Coordinator for the Deaf from the state of Minnesota, Ruben Latz.

**Ruben Latz:**

It is a great feeling to be here today and see many of my deaf friends in the audience and my SCD colleagues on this panel.

Similar to Ohio, Minnesota has a fairly rural population. The numbers breakdown in Minnesota is very similar to Ohio's numbers as well. We have 23 or 24 staff now around the state who serve deaf, hard of hearing, and late-deafened individuals. In the twin cities, we have six RCDs for Minneapolis and St. Paul who are all fluent signers. State VR staff in our rural offices have varying degrees of expertise in sign language. In addition, we have some mixed caseloads, where a couple of counselors are serving a mix of deaf, hard of hearing, and general caseload clientele.

First and foremost, Minnesota employs a number of deaf and hard of hearing specialists on the counseling staff along with a cadre of Vocational Communication Specialists (VCSs). Many people call them interpreters who are trained to anticipate and respond to needs of hard of hearing and late-deafened adults.

At intake, as well as throughout the planning and service delivery process, we work toward respecting the individual client and making a good faith assessment of their individual situation. We try to assure that they have communication access to VR programs and services.

This translates to being thorough in the information gathering process, giving full consideration to identifying workplace communication barriers, and being creative problem-solvers. Counselors can use their caseload service funds to purchase such items as FM systems and digital hearing aid technology. Sadly, current state VR policy prohibits us from doing cochlear implants.

We also try to take a team player mind-set into the rehabilitation process. Field office staff are gathered at least annually – sometimes twice a year when budget permits – for training meetings, which typically are 2 days long. This commonly includes a refresher or overview on what's new in rehabilitation technology and what's new in hearing aid technology. We work closely with clinical and dispensing audiologists to assure ease of client referrals for testing and fitting, as well as consulting with them on what's new.

Specialist staff are also supported by our training department for consultation and problem solving. Also, middle managers – such as my position – are encouraged to seek opportunities to participate in local, regional, and national events. Counselors and vocational communications specialist staff also serve on various community and agency boards of directors, advisory committees, and related work groups. We're encouraged to keep abreast of legislative initiatives, as well as changes in policies and emerging technology.
The month of September, we have a series of 10 "fall forums" being hosted around the state by a sister agency, the Department of Human Services (DHS). Those forums are conducted with the help of the Deaf and Hard of Hearing Services Division as well as the Minnesota Council Serving Deaf and Hard of Hearing Persons. People have asked, "What are the distinctions between our agency, DHS, and the council?" We are separate at the department level; the council is supported by the Deaf and Hard of Hearing Services staff. As the meetings happen around the state in the next few weeks, we will be looking at consumer input as to what their legislative, community, and state needs are to further support the needs of our consumers.

Emerging technology has recently drawn attention in Minnesota, particularly the use of remote interpreting and Remote Access Technology (RAT). One of our colleagues that many of you know, Alan Parnes (an RCD in the Minneapolis office), has spear-headed the development of a work and demonstration group now underway to promote RAT interpreting. The feedback that we're getting is extremely positive. That partnership includes the Department of Human Services, the Department of Health, and the Minnesota Foundation for Better Hearing and Speech which is a private, nonprofit group.

Related to the remote interpreting demonstrations and Remote Access Technology, Minnesota has also worked to enact "one-stop employment center" legislation. Many of you are aware of similar work force legislation in your state. For us, that means as a state department we are partnering with the city of St. Paul as well as with other cities or locations where other "one-stop" offices are located. These also include county office staff. Altogether in Minnesota, we have 49 partnered offices, and we will have another five or six by the end of the fiscal year. We have to make changes in terms of how we do our business, how accessible we make our services, and how we will train other departments and agencies to make their programs more accessible. The "work force one-stop center" legislation is going to take a long time to implement, but it's something that you need to know about. If you're not familiar with what is happening in your state, I'm sure that you will see it soon.

The other emerging technology we are seeing more and more frequently in Minnesota is Computer-Assisted Realtime Translation (CART) captioning services. I can't give you exact numbers, but do know that one of my office colleagues is regularly a user of CART services.

To sum up, our deaf and hard of hearing specialist staff in Minnesota try to work responsibly with late-deafened consumers. However, we are also, like Ohio, an "order of selection" state. I believe that we are trying our best to provide full respect and consideration for unique needs of late-deafened adults. I believe that the future lies in collaborative efforts. This includes, for example, working with your state to assure that work force center partners learn what they need to learn in order to deliver a successful program of services for late-deafened individuals.

**Douglas Watson:**

Our next panelist is Barbara Gurga who is employed as a local Chicago-area Rehabilitation Counselor for the Deaf (RCD), serving a deaf and hard of hearing caseload.

**Barbara Gurga:**

We have about seven RCDs who have caseloads of deaf and hard of hearing customers in the Chicago area. We all have a caseload of between 120 to 150 customers. These are mixed caseloads for the most part, a mix of individuals who are Deaf, late-deafened, and hard of hearing.
I have been an RCD for 11 years. I have had numerous experiences working with late-deafened consumers. For the most part, these people came to our agency to ask us to help provide them with effective communication skills. That includes training to improve their interpersonal skills.

I think these were two of the major areas in which they felt they needed to develop their skills. Many didn’t know what to do because they had experienced an adult onset hearing loss and didn’t know sign language. They didn’t know what other methods of communication they needed to learn in order to be able to communicate with peers or other people who have no knowledge or experience in communication with people who have just recently lost their hearing.

We have an organization here in Chicago that I often work with which is called Hearing Loss Link. It’s an outstanding organization of people. I think they do an outstanding job assisting individuals with adult onset deafness to make life and career adjustments.

There’s also a Chicago chapter of the SHHH organization. There are many different kinds of such consumer organizations. In order for the counselor to be able to help people who are late-deafened, we need to know what they need and what is their preferred mode of communication. The same rule of thumb applies also for training programs, colleges, work sites, and other areas where late-deafened individuals feel they need to have assistance in order for them to be able to communicate.

We need to develop more resources for people who are late-deafened, and increase and strengthen the local and national network. We know that ALDA has a convention once every year. I think they need to have some kind of a system where they can contact other persons to help identify other available resources to help them maintain the communication skills they need for day-by-day social interactions.

We also need to set up some form of support system that would enable us to assist each late-deafened VR customer to live and work independently in the community. Chicago-based RCDs have worked hard to become more sensitive to and aware of various ways and means to better serve the unique rehabilitation and communication needs of late-deafened individuals. We’re always trying to see what new services we will be able to find in order to meet their needs. It is our hope we will see some growth here in Chicago as well as throughout the United States.

**Douglas Watson:**
Our last panelist is Ellen Roth, State Coordinator for the Deaf in Illinois, who works out of the Chicago office.

**Ellen Roth:**
I'm an SCD. I'm a manager and work within the Department of Human Services. That's our agency, the parent agency. There are eight smaller agencies underneath the parent agency. Our branch is called the Office of Rehabilitation Services.

After World War I, war veterans who returned to civilian life with disabilities, such as hearing loss, blindness, or deafness, often found they had no jobs to come back to. So there were a lot of things that had to be done. New training programs had to be set up in order for them to receive the help they needed to return to a normal life as a civilian. That's why the
Federal/State Vocational Rehabilitation program was established. It was established in order to provide a way to help these individuals.

Nowadays, the VR program serves a much broader segment of the population which ranges from people who have been disabled since birth to those who have acquired disabilities during their adult years. This means that we now have to address a much broader range of hearing loss. The rehabilitation community previously focused on developing and delivering services for Deaf people who were members of the Deaf community and culture. The idea was that most children who had lost their hearing in childhood were sent off to "center schools for deaf students" or "residential schools." That's where they got their vocational training and assistance to make a successful transition from school to work. As a consequence, educational and rehabilitation programming for Deaf children, youth, and young adults evolved around the residential school or "center schools for deaf students" in the various states.

State VR services and school programs serving Deaf students thus formed close working partnerships as many states set up VR units right on the campuses of Deaf education programs. As far back as the mid-1940's. By way of contrast, it is only in the past decade that the VR program has begun to really acknowledge and organize its efforts to serve hard of hearing people and people experiencing adult onset deafness. State VR programs now recognize that each group has different needs.

Illinois now has 33 RCDs who carry caseloads of Deaf, late-deafened and hard of hearing individuals. These 33 RCDs are employed as specialist counselors throughout the state. They are serving mixed caseloads of individuals who are Deaf, hard of hearing, late deafened and/or deaf-blind.

It can seem confusing at times because some of these RCDs are themselves deaf or hard of hearing, while others have normal hearing. There are various ways by which we can assess and determine the skills that various RCDs bring to the job. One measurement we use is the Sign Communication Proficiency Inventory (SCPI). This is a communication skills assessment and evaluation process which measures and classifies sign language communication skills of counselors and identifies their level of sign language skill on an intermediate level of skill or higher. Those who have sign language skills must score up to an intermediate level. They are also required to have a masters' degree. In other words, we are looking for more qualified personnel with high levels of skill.

Currently, Illinois has set up five service regions for deaf and hard of hearing services. I'm a manager in the Chicago area office. We also have two or three deaf people who work with deaf-blind caseloads in the state.

We hold monthly meetings with the RCDs and have an annual statewide counselor meeting. We want to make sure VR services are maintained and improved throughout the state for all customer groups. That includes providing for the variety of communication preferences people have, including those who have a variety of hearing losses.

Traditionally, Illinois has annually dispersed a very large number of hearing aids. But now new technology involves cochlear implants. These operations/implants are quite expensive. There are ten people who have received those services. We also purchase technological equipment such as vibrator alarms for deaf-blind individuals and other such alerting systems. Many of our customers request assistance to obtain access to that technology.
Please understand, now, that purchase of such technological aids and devices has to be justified. State VR has to have reason to believe that it will help our customers be more independent, enable them to work independently and function in their job. For deaf people like myself, maybe a laptop computer would help, but state VR services would have to justify each purchase that it makes. It varies, and changes are occurring in client choices all the time.

A good example would be the state VR funding that's being allocated to fund different programs to provide services for people in the community. Money from the Illinois VR agency was allocated, for example, to establish and operate the Hearing Loss Link program that's been established in Chicago. Bill Graham, one of the founders of ALDA, was also a founder of Hearing Loss Link. The program is set up to serve individuals who have adult onset hearing loss or are late-deafened. They provide a variety of services, including information, referral, and advocacy services. This is an important program for those who suddenly find their life being impacted and changed as when a person goes from being hearing to being deaf in one day.

Another example might be the state VR contract with the Chicago Hearing Society. Department of Public Aid funds were given to Chicago Hearing Society. The goal of that initiative is to provide free interpreting services so that deaf people can fully participate in meetings or whatever event they attend. That program has been in operation for the past 9 years and state VR money has been set aside for that.

More customers need to learn how to take advantage of that service. For example, if a late-deafened individual wants to go to a meeting and doesn't understand sign language, they are in need of CART services. Previously, people thought that CART services were not eligible for funding. When they came to me, I looked at the definition and noted that the funding award explanation said "communication access." So, I ruled that the program would expand the definition of services. We have now implemented CART services, along with captioning and interpreting services. The funding was approved over a year ago. The grant is now open to anyone using any type or mode of communication, not just interpreters. That's an important change that's happened recently, and I'm very happy to say that it has happened. At this time, it is funded only in the Chicago area. It's not yet a source for statewide funds to be used for anyone throughout the state – only for Chicagoans.

But a year ago there was a law passed to establish an Illinois Commission for the Deaf and Hard of Hearing. The commission is also going to be coordinating activities with VR. We expect that late-deafened persons will be appointed to the commission's governing board. These board members will be involved with the proceedings that will select a new commissioner to head up the agency.

**Douglas Watson:**
It seems that a lot of exciting thing are happening around the region. The panel will now take questions or comments.

**Audience Member:**
Are any of your agencies doing research on making use of voice recognition computer software programs? There is a computer software called *Dragon Naturally Speaking*. It would appear to have great potential benefit and use for deafened and hard of hearing people who live in rural areas who do not know sign language. It's hard to learn sign language. The use of voice recognition technology might be cheaper, too.
George Kosovich:

We have several rehabilitation engineering centers which are researching the voice-to-text technology. This is probably one of the areas that is getting closer and closer to realization. There was a demonstration of that technology at the recent SHHH convention in Phoenix, Arizona. It was very impressive and we have looked into it. Several research centers have initiated research proposals to NIDRR to investigate that. The problem is that technology limits the program for use by only one person's voice or speech at a time. So it's not something you can pass around and bring up whatever anybody says. But it could be used by a communication facilitator whose voice is programmed into the computer to repeat what other people are saying in a meeting or in a classroom or wherever. It could probably even be used by relay operators so they wouldn't have to type what's being said, it would print out text into the user's TTY. So that technology, I feel, is pretty close to becoming a real tool we can harness and use.

Costs remain a key issue. Like we discussed in an earlier session, interpreter services for a university or college student can cost upwards of $20,000 a year. CART services can cost even more. Plus, as more and more students with hearing loss are mainstreamed, programs will realize these traditional communication accommodation services are going to become prohibitive in terms of cost. Cheaper alternatives are needed. Some of us believe that voice-to-text technological applications may prove to be one possible alternative.

Which brings up the question of whether any of you have heard of C-Print? C-Print has been developed at the National Technical Institute for the Deaf (NTID) at Rochester, NY. It's basically used on a regular computer keyboard and has a program which allows the operator to initialize commonly used words. This approach allows the typist to use a regular keyboard, not the court reporter's stenograph machine, to provide verbatim notes. Some of our people in the research area are looking at developing training with the C-print system. NTID is doing some training in that particular communication mode. So, there's some great developments underway. Obviously, many of you folks aren't hearing about these new developments, so maybe we need to let people know what's going on in research a bit better.

Ellen Roth:

Let me add something to what Kosovich said. About the voice-to-text recognition software: 5 years from now there will be much better micro processors. They're going to be more powerful with larger memory, space, and smaller chips. The capabilities for that program will be more powerful and capable of doing anything, going anywhere and being packaged on a laptop. That would make it portable and users could take it anywhere they go, any meeting they attend, any classroom, with any person that they might meet. All they would have to do is open the laptop and proceed to communicate.

One IBM engineer told me it was going to be happening in the very near future. So, I guess we can start to plan for it soon. As we can see, computer chips and processors are improving daily.
George Kosovich:
Here is a question for the audience, "Are any of you having problems or concerns about the issue of who pays for interpreting services or other auxiliary aids and services?" No problems? Have you heard any problems?

Audience Member:
I work with PEPNet. We are covering 14 states now. An issue we are seeing is that state VR programs don't want to pay for auxiliary services. We think it's a big issue and believe that VR needs to pay for auxiliary aids, or at least agree to split the cost with educational institutions rather than expecting the institutions to take it on. Their interpretation that ADA has replaced the Rehabilitation Act is wrong. So that's a big issue that we see. I know RSA is hearing about it a lot. I hear about it a lot through my contacts with colleges and universities. That's a big issue.

Ruben Latz:
Let me make a quick comment in respect to the point about costs. In Minnesota, on the caseload I just left, I started fiscal year 1998 with $64,000. That $64,000 was intended to serve over 100 people. So in spite of our best wishes, our best dreams and hopes, we do face daily financial realities in the form of budget limitations.

That being said, Minnesota is one of the states that doesn't do cochlear implants. That's simple. We have the same freedom that you do to select and provide appropriate support services, but the financial reality is – if I spend $38,000 on one individual, what do the other 119 people get that year from my caseload?

There was some earlier comments about the nonpayment of auxiliary services that I would like to clarify. Minnesota VR does pay for auxiliary services; we don't want to pay any more to support interpreters in postsecondary institutions. There is a little bit of distinction that needs to be made there. But we do try to meet individual needs.

Skip Berquist:
In Ohio, we don't provide cochlear implants; but we do assist consumers in finding other sources of support such as insurance, hospitals, or other ways to fund implants. For the most part, we have been successful. However, we have to watch the costs and serve as many people as possible. There are some restrictions; but there are ways we can utilize other sources. Money is a big issue with rehabilitation. There's not enough money out there. RSA requested $3 billion, but was given only about $2.3 billion this year. Chronically short of money, the Federal/State VR program cannot serve all the people who need state VR services. VR counselors always have to struggle with their budgets and sometimes have to say no. It's not easy to do that, especially when we really want to help customers reach their real potential. We have consumer-choice options in effect now, and we have people saying, "I want to do this or that." State VR counselors want to support customers in the choices they make, but adequate funding is not always available.

So it's possible that an RCD might support a client's interest in attending graduate school and that kind of thing, but lack the financial resources to assist them in covering the attendant costs. We advocate increasing client freedom and choice; but do we have enough money to assist their exercise of those freedoms and choices? These are tough issues for our RCD counselors who are having to say "yes" and "no" in different situations. We need to be looking at how to do this the best way we can and still serve all the people who want and need VR assistance.
Audience Member:
Let me say that the VR counselors, particularly the state VR program in Illinois, have come a long way. I was out of the work force for about two years after becoming late-deafened and went to VR for assistance. I thought I was ready to cope and ready to find a job, but they sent me to a VR counselor in Chicago. I had to put little blocks and little squares together and draw pictures of trees, etc. Plus, the evaluation team and counselors were signing to me very proficiently. I had no idea, no clue, of what was going on. But they said, "We have the perfect job for you with your skills." Actually, they never did ask me what my skills were because I had no idea either. I was eventually hired by the Department of Transportation. That was almost 12 years ago and I'm still there. They more or less had to fill a quota, and that was me. So, there I was, the only deaf person out of 600 employees.

Apparently, the company thought they had a perfect situation – since I am deaf and they had one deaf woman employee, she could train me to do the job. Well, she did not speak; she communicated only by signing. I had no idea what was going on.

To make a long story short, I requested CART services and now regularly use CART every week. I also have a personal typist who doubles as a skilled interpreter. So sometimes you need to advocate for yourself. Self-advocacy can be very, very hard, but sometimes its the only way to make real gains.

Audience Member:
When you receive a referral, do you try to find out what the communication and accessibility needs for the person are before the first interview? How do you know? How do you get ready for that person?

Barbara Gurga:
When we do the intake, we ask them about both their primary disability and their preferred mode of communication. When they come in for their appointment, immediately start to communicate with them in their preferred mode. So, it depends on the individual.

Ruben Latz:
Each Minnesota field office handles intake differently. On first contact, whether it's drop-in, via a phone call or e-mail, we begin to gather data. Beyond that, we make whatever accommodations are necessary.

In the twin cities, at the Minneapolis and St. Paul offices, even the reception staff have taken some basic sign communication courses over the years. Often deafened clients will have the opportunity to learn to sign from their interactions with the primary receptionist who might be in the office at that moment. We often use the computer keyboard. We do whatever it takes to try to meet communication needs.

Douglas Watson:
Thank you. I'd like to thank the panel for their excellent presentations. In closing the program, I would like to add that one of the primary mandates for my own research center at the University of Arkansas is to study what is happening in the rehabilitation service delivery system that addresses the special needs of people who are hard of hearing or late-deafened. To its credit, the rehabilitation community is actively looking for ways to creatively deal with emerging problems and needs presented by late-deafened individuals. This panel reflects the fact that state VR agencies are not sitting back and ignoring late-deafened people, but instead are very much aware of their special needs.
I believe this effort has been stimulated in large part due to the impact that ALDA itself has had. The group of late-deafened people who got together and set up this organization have stimulated the beginning, I think, of a growing nationwide awareness, understanding and response to the needs of late-deafened people throughout the 50 state VR programs. I would recommend that ALDA continue to encourage its members and affiliates to actively seek out contact with state VR programs in order to advocate for and involve themselves in leadership roles within the state rehabilitation consumer advisory council, independent living advisory councils, and so forth.

ALDA needs its membership to be actively involved in ongoing efforts to advocate for the rights and needs of people who are late-deafened. ALDA and its advocates need to work together to educate programs and people involved in the disability field about the special needs of late-deafened individuals. ALDA needs to be counted, to be seen, to be heard.

In closing, let me express my regret that time constraints precluded my talking in depth about our research program at Arkansas. However, I encourage interested readers to also take a look at the paper in this book by Steve Boone in which he describes other University of Arkansas research and development activities related to job-seeking skills training packages for people who are hard of hearing or late-deafened.

Last but not least, we invite you to visit us at our Internet website address: http://www.uark.edu/depts/rehabres. Our Center's website includes information about the Center as well as the various projects underway at the University of Arkansas Rehabilitation Research and Training Center for Persons who are Deaf or Hard of Hearing (RT-31). We encourage you to visit our home page and review the various activities underway. We also invite you to make use of the information and resources our Center can make available to assist you in your efforts to improve rehabilitation and employment outcomes for individuals who are late-deafened.

Speaking on behalf of the panel members from the Federal/State VR program, we would like to close with this message: we hope you and other ALDA members will continue to work with us – you’re our audience, you’re our customers. The various state VR programs really need to hear from you, and need for you to be represented on their respective state VR consumer advisory councils back in your home states as well as at national ALDAcons. Let’s work together to make it happen!
WHAT IS PEPNet AND WHAT CAN IT DO FOR ME?

Sharaine J. Rawlinson

PEPNet

PEPNet, the Postsecondary Education Programs Network, is the national collaboration network involving four Regional Postsecondary Education Centers for Individuals who are Deaf and Hard of Hearing. The Centers are supported by contracts with the U.S. Department of Education, Office of Special Education and Rehabilitative Services. The goal of PEPNet is to assist postsecondary institutions across the nation to attract and effectively serve individuals who are deaf and hard of hearing.

THE FOUR REGIONAL EDUCATION CENTERS AND THE PEPNet MISSION

The Regional Postsecondary Education Centers for Individuals who are Deaf and Hard of Hearing were created in 1996 to ensure that every postsecondary institution in the United States could easily access the technical assistance and outreach services that the Centers provide.

The mission of PEPNet is to promote opportunities for the four Regional Postsecondary Centers for Individuals who are Deaf and Hard of Hearing to coordinate and collaborate in creating effective and efficient technical assistance to postsecondary educational institutions, thereby providing access and accommodation to individuals who are deaf or hard of hearing.

PEPNet OBJECTIVES

- To improve postsecondary access and transition opportunities for individuals who are deaf or hard of hearing.
- To develop a national network for technical assistance and outreach service delivery to assure that postsecondary institutions and the students they serve will benefit from PEPNet's collaboration and coordination efforts.
- To expand the knowledge and skill of postsecondary institutions related to the provision of educational support services for deaf and hard of hearing students.
- To increase networking among postsecondary educational institutions.
- To increase the postsecondary enrollment, retention, graduation, and employment rates of students who are deaf and hard of hearing.
PEPNet STAKEHOLDERS & TECHNICAL ASSISTANCE SERVICES

The four Regional Postsecondary Education Centers for Individuals who are Deaf and Hard of Hearing provide technical assistance and facilitate a collaborative network of communication and consortia among:

- Two-year colleges
- Four-year colleges
- Vocational training and rehabilitation programs
- Adult education programs
- Private and public community service agencies
- Deaf and hard of hearing individuals
- Consumer and professional organizations
- State and national organizations
- Clearinghouses

PEPNet and the four Regional Postsecondary Education Centers for Individuals who are Deaf and Hard of Hearing provide these services to postsecondary educational institutions:

* Access to a collaborative network among the four Regional Postsecondary Education Centers for Individuals who are Deaf and Hard of Hearing, postsecondary institutions, national clearinghouses, community-based organizations, professional and consumer organizations, federal and state agencies, research and training centers, and other stakeholders with an interest in postsecondary education for individuals who are deaf and hard of hearing.

* Consultation and training for postsecondary administrators, faculty, and staff to enhance access and accommodations for deaf and hard of hearing students. Training topics include, but are not limited to:

  ✓ Transition and student evaluation
  ✓ Professor/instructor in-service
  ✓ Counseling techniques
  ✓ Development of student plans
  ✓ Deaf/hard of hearing awareness
  ✓ Tutoring
  ✓ Notetaking
  ✓ Interpreting

  ✓ Curriculum accommodation
  ✓ Grant writing
  ✓ Vocational assessment development
  ✓ American Sign Language
  ✓ Realtime captioning
  ✓ Assistive listening devices
  ✓ Other communication methods and technologies

* Dissemination of information to postsecondary institutions about the resources and services available to them through PEPNet and other regional and national organizations, agencies, and information clearinghouses.
For more information, contact the center in your region:

The **Midwest Center for Postsecondary Outreach** (MCPO) is located at Saint Paul Technical College, St. Paul, Minnesota. For over 25 years, St. Paul Technical College has been a leader in providing technical education and assisting deaf and hard of hearing students from across the U.S. to successfully complete career training and become gainfully employed. MCPO serves the Midwest Region, which includes the states of Iowa, Illinois, Indiana, Kansas, Ohio, Michigan, Minnesota, Missouri, Nebraska, North Dakota, South Dakota, and Wisconsin. 651-221-1337 voice/TTY, 651-221-1339 fax, or e-mail: rolson@stp.tec.mn.us.

The **Northeast Technical Assistance Center** (NETAC) is located at the Rochester Institute of Technology in Rochester, New York. NETAC will be supported by one of RIT's colleges, the National Technical Institute for the Deaf, the world's first and largest technical college for deaf students. NETAC's region includes the states and territories of Connecticut, Delaware, District of Columbia, Maine, Maryland, Massachusetts, New Hampshire, New Jersey, New York, Pennsylvania, Puerto Rico, Rhode Island, and Vermont. 716-475-6433 voice/TTY, 716-475-7660 fax, or e-mail: netac@rit.edu.

The **Postsecondary Education Consortium** (PEC) is located at the University of Tennessee at Knoxville. Initiated in 1983 with four affiliate postsecondary institutions, the PEC now includes 10 affiliate programs across the South. Under this new contract, the PEC serves the Southern Region which includes the states and territories of Alabama, Arkansas, Florida, Georgia, Kentucky, Louisiana, Mississippi, North Carolina, Oklahoma, South Carolina, Tennessee, Texas, Virginia, Virgin Islands, and West Virginia. 423-974-8427 voice/TTY, 423-974-3522 fax, or e-mail: pec@utk.edu.

The **Western Region Outreach Center and Consortia** (WROCC) is located at the National Center on Deafness at California State University, Northridge. Since 1963, the National Center on Deafness has been a leader in the development and delivery of innovative support services to the highest number of deaf and hard of hearing students enrolled in a mainstream university in the region. WROCC serves the states and territories of Alaska, American Samoa, Arizona, California, Colorado, Guam, Hawaii, Idaho, Montana, Nevada, New Mexico, Northern Marianas Islands, Oregon, Utah, Washington, and Wyoming. 888-684-4695 voice/TTY, 818-677-4899 fax, or e-mail: wrocc@csun.edu.

*More information can also be found by visiting the PEPNet website at [www.pepnet.org](http://www.pepnet.org).*