Addressing the Needs of Late-Deafened Adults
Changing Lives in Changing Times

Addressing the Needs of Late-Deafened Adults

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Selected Proceedings of ALDAcon '95

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EDITORS NOTES AND ACKNOWLEDGEMENTS

The University of Arkansas Rehabilitation Research and Training Center for Persons who are Deaf or Hard of Hearing is pleased to have prepared and published "Changing Lives in Changing Times: Addressing the Needs of Late-Deafened Adults". This book focuses on material presented at the ALDAcon '95, 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. Dedicated 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.

The conference convened October 4-7, 1995 in Rockford, Illinois. The annual "Meeting of the 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 the conference planning committee under the leadership of Kathy Schlueter. As evidenced by the number of persons in attendance, it was clear that the conference did and hopefully, will continue to provide a forum for consumers, service providers 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. As editors, we would like to especially thank all of the presenters for their timely preparation of the 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 would also like to sincerely thank the leadership and members of the ALDA board, both past and present, for their cooperation during the completion of this manuscript.

Steven Boone
Douglas Watson
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AUTHOR BIOGRAPHIES

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Steven Boone, Ph.D. is a Research Professor and Director of Research at the University of Arkansas Rehabilitation Research and Training Center for Persons Who are Deaf or Hard of Hearing. He has over ten years experience in conducting applied research targeted to enhancing the social and job-related interpersonal skills of persons who are hard of hearing or deaf. He has conducted over 100 presentations and workshops at national and regional conferences and has authored, co-authored, or edited over 40 chapters, journal articles, monographs, or books. Dr. Boone is an active consultant to business and community agencies in areas related to his research, use of technology, and the Americans with Disabilities Act.

Mary Clark is the Communications Specialist for Chicago Public Schools. She provides support for the 35 interpreters within the system and works with administrators and other personnel to evaluate, educate, and advocate for mainstreamed student communication needs. Mary has taught Deaf and hard of hearing children, worked as a Deaf Services Coordinator, served as Resource Manager for the Illinois Relay Center, and was Executive Director of a Center for Independent Living. As a late-deafened adult, Mary freely admits to being an ALDA addict.

Cheryl Heppner is the Executive Director of the Northern Virginia Resource Center for the Hearing Impaired in Fairfax. She married her sidekick, Fred, 22 years ago when she had a moderate hearing loss, but together, they have coped with the enormous changes required when Cheryl's hearing deteriorated further.

Diane Jones received her bachelors and masters degrees in Deafness Rehabilitation Counseling from Northern Illinois University. For the past four years at the Center for Sight and Hearing Impairment, she has worked as Instructor/Counselor for the hearing impaired. As an instructor, she has taught sign language and speech-reading classes to persons who are late-deafened. As counselor, she has provided adjustment counseling to assist individuals and their families to learn to cope with hearing loss. In January of this year, Diane was promoted to Director of Professional Services and is responsible for programs and services in both the visually impaired and hearing impaired programs.
Nancy Kingsley is the ALDA Chapter Coordinator (providing information on starting and leading ALDA groups), the editor of the Leader Letter for ALDA leaders, and the founder/leader of ALDA-NJ. Among her other accomplishments, she has facilitated a support group for people with hearing losses and serves as the Community Services Chairperson for the Advisory Council to the NJ Division of the Deaf and Hard of Hearing.

Roy E. Miller is a past president of ALDA. He is a frequent e-mail user and established the Deaf-L electronic mail exchange. Dr. Miller is currently employed as Professor of Political Science at Southern Illinois University in Carbondale, IL.

Laura Thomas Roebal is the Regional Representative for the Helen Keller National Center's North Central Region located in Chicago. She has many years of experience working with adults who are deaf blind. She worked for a number of years at HKNC's Center in New York as a case manager and supervising the case management department.

Dayl Scherich, Ph.D. was previously a Research Assistant Professor at the University of Arkansas Rehabilitation Research and Training Center for Persons Who are Deaf or Hard of Hearing. Dr. Scherich has conducted applied research targeted to enhancing employment opportunities for persons who are hard of hearing or deaf since joining the Center in 1992. Prior to that time, she was an audiologist for thirteen years in the public and private sector. Her current research looks at the current practices and needs of workers who are hard of hearing or deaf, and assessing and improving community service centers which provide vocational services to individuals who are hard of hearing or deaf.

Carol Slinsky graduated from Gallaudet University with a Master's Degree in social Work. An advocate for deaf and hard of hearing people, she serves or has served on the boards of many organizations that focus on the needs of deaf and hard of hearing persons such as the Maryland Relay, Telecommunications for the Deaf, and Self Help for Hard of Hearing Persons. She received a cochlear implant in 1992. She is currently working as a Mental Health Specialist for the Nebraska Commission for the Hearing Impaired.

Judy Tingley is a new member, and the only one who is deaf, at the First Unitarian Society in Madison, Wisconsin. She uses a sign language interpreter for the Sunday service and has just begun to participate in other activities of the church such as Circle Suppers, folk dancing, and a 4-week orientation course.

Robin Titterington is the current President-Elect of ALDA. She is a member of Holy Trinity Episcopal Parish in Decatur, Georgia, where she is the only deaf member and uses a sign language interpreter. In the past, she has taught Sunday School to deaf children and served on the administrative council. She is currently a member of the Lay Pastoral Committee.
Wow, I'm honored to be here. It's hard to believe that I've been serving on the board for about nine months now. What a learning experience! First, I have to say "thank you" to my fellow board members. These people work SO very hard for you and deserve your thanks. It's been a joy.

Our theme this year is "changing times" and I thought, as a way to introduce myself to you, I would tell you a little about my changing times as a late-deafened adult and see if perhaps they parallel ALDA's growth in some ways.

I became deaf from a medicine when I was 19. That was about three years ago. HAHHAHA! No I lie, that was really about 20 years ago and alas, there was no ALDA then. There were very few TTYs, no relay services and no captioned television. I was in college at the time, and as soon as I got well I went back to my hearing college for two reasons: I didn't know of any other options and my daddy threw me out! No, I'm kidding, but education was very highly valued in my family and it was expected that I return to school.

I could relate to Holly's article in our last ALDA NEWS when she stated she could hear fine, she just couldn't understand and it was really other people's problem, not hers. That pretty much sums up how I felt at the time. After about a year, a wonderful counselor pushed me to go to Gallaudet for one semester. The purpose of that stay would be to increase my lipreading skills. I remember telling one of my dearest friends that I was going to miss a semester of school, but that it was for a good reason: to learn to lipread. I'm not making this up. Her response, nearly in tears, was "but you're going to learn to read YANKEE lips!!"

So off to Gallaudet I went. This was in 1976 and Gallaudet was not quite ready for a person in a wheelchair. Their rather unique definition of "reasonable accommodation" was "Steve
Larew." Yes, Steve and I probably became closer than we ever wanted to be in those days. I won't discuss how many times he carried me into the college bar!

At this point, I should explain about how I was nominated for your President-elect position. Last year, Jerry Barnhart called me and asked me to allow my name to be on the ballot. I thought it over for several days, and although I was deeply honored, felt I could not make the commitment. Jerry, being the gentleman that he is, accepted that. A few days later I got another call from Steve, asking me again to consider the position. When I refused, Steve went for my weak spot. He promised me chocolate, LOTS OF CHOCOLATE. Nine months into my term, I can report that, to date, I have received THREE chocolate bars. Fellow members, I ask you--does this seem appropriate? I suggest you all speak to him after this session!

After I graduated from college, I went on to New York University to begin my graduate work in Deafness Rehabilitation. This was not done because I felt a calling to serve deaf people. I suspect it was more to try to figure out what was happening in my own life. At any rate, I improved my signs some there. When I graduated, I moved from New York City to Rome, Georgia. If that doesn't show you I can be a flexible board member, nothing will!

I stayed in Rome for 18 months before I relocated to Atlanta. I truly feel I had an advantage that most of you did not have when you became deaf. I moved to an entirely new state where no one knew me as a hearing person. There was no one in Georgia thinking, "oh, it's so sad, I remember when she could hear." When I moved to Georgia, I became involved in the Deaf community. I know many of you have had some unfortunate experiences venturing into this community and that makes me sad. But as I said, there was no ALDA and I was not satisfied with communicating with just a few people at a time. I don't know if it's the Georgia hospitality but I have never felt pushed out in the Deaf community there. There are Deaf people that I am closer to than my own family and I cherish my role in that community deeply. And I would like to mention that Andy Lange is here. Andy was recently elected
president of the Georgia Association of the Deaf and it means a great deal to me to have that part of my "family" represented here.

I went along for about 15 years, doing just fine. And then one day a copy of ALDA News popped up on my desk and, suddenly, everything changed again. My first thought, was this was the funniest newspaper I had ever seen. I loved the stories and the jokes. I couldn't wait to get to an ALDAcon. Since that time I have become more and more involved with the newsletter, the Cons, and the people. I've learned it's OK to miss talking to strangers on the plane. I've learned it's OK to feel frustrated on the job because I can't participate in the small talk. I've learned I can be sad that my family doesn't sign, but know that they still love me and I still love them. I've learned that I'm not the only one who feels stupid when I misunderstand someone who I'm trying to lipread. I've learned it's OK to SING, even if you don't do it well!

So, what are my expectations as ALDA president? First, anyone who has talked to me in the last year, knows that communication with members is my number one priority. That's what we are here for. Last year, Nancy Kingsley sent me the name of a late-deafened adult in my area and asked me to call him. She said the number was a TTY number, but I couldn't get a response that way. After some delay, I finally did get to talk to the gentleman on the TTY. We had a very nice talk and he was very enthusiastic about ALDA. At the end of our conversation, he said, this has made my day! In the seven years I have been deaf, this is the first telephone call I have received!" NO adult should go seven years without getting a phone call. Each of us needs to be reaching out to other ALDAns.

We do need to spread the word of ALDA. I'm expecting every one of you to wear your buttons, your hats, and carry your totes and newsletters wherever you go. Let me tell you a story about the challenge we face. As some of you know, I am director of the Georgia Interpreting Services Network (in my "other life"). When the network was set up eight years ago, I told my staff to go all over the state and let state agencies know we were now liable to
interpret for their deaf clients. One of my staff members went up into the Georgia mountains and found a little office that seemed to be a combination health department, food stamp office and rehabilitation services office with one older gentleman at the desk. He sat with his feet on the desk, smoking a cigar. That was in the days when you could still smoke in state buildings! Anyway, Shirley did her usual fine job of explaining our services and how we could make communication easier for both the gentleman and his clients. However, she did not seem to be getting much of a response. Finally, she asked, "well, do you think you will have any need for our services? Do you get any deaf clients here?" His response was, "No, the old ones all done died off. The young ones all moved south to the braille school." True story. We have an identity problem!

Let us focus on "reaching out in 1996." You all know that in 1996 Atlanta will be hosting the Centennial Olympic Games. As I think of the athletes from all over the world coming together, many cannot communicate with each other. Yet they come together with a common purpose. It reminds me of our special communication through our newsletter, through the BIZ, through our ALDAcons. The technology is tremendous, but our best resource is our people. I would like to close with one thought from Helen Keller, "The best and most beautiful things cannot be seen or even touched. They must be felt with the heart." That is ALDA to me. Thank you!
Hi. I'm glad to be here this morning and have the opportunity to talk with you about the needs of late-deafened adults within the service delivery system. As you know, my name is Mary Clark and I am late-deafened myself. I have had the experience of working with other late-deafened individuals as a trained leader and participant in support groups. I have also been specially trained to go around the state of Illinois and educate other professionals on the needs of late-deafened adults. As a Deaf Services Coordinator and Executive Director of a social services agency, I work with and set up programs for late-deafened adults. I understand how important it is for service providers and professionals in the rehabilitation field to understand the needs of late-deafened adults so that they can better provide services and address the needs for adjusting and coping with the hearing loss.

Just who is in that group we are talking about? It's important to remember that when we are talking about some of the generalities describing our population group, that many individuals with hearing loss identify with the functional level at which they see themselves. Many service providers look at it from a decibel or audiological loss and set up a service delivery system based only on those numbers. We need to respect the choice of a group identification that an individual makes. For example, someone who has a profound hearing loss might consider themselves to be hard of hearing. They may or may not use sign language and they may use amplification and function well enough to talk on the phone and on a one-on-one basis. In general, however, late-deafened individuals have a severe to profound loss. Some use amplification or have cochlear implants and others don't. Most late-deafened individuals derive little or no benefit from assistive listening technology. For example, amplification benefits me very little. It is possible I would know when someone was trying to get my attention or something was going on in my environment, but I would not be able to identify what exactly it was. Individuals who are late-deafened usually acquire their loss after the development of speech and language. In my case, hearing loss was discovered in one ear in
elementary school. Hearing in my other ear deteriorated around the age of 13 and then rapidly deteriorated further after my second child was born. So I already had my language and speech, and for some reason I have been able to retain the quality of my speech. Most individuals in this population can benefit from the use of visual display technology. Most rely on visual representation of English as their primary language. ASL or sign language is a second language for these individuals, but some may use a system of signing and some may not. Usually late-deafened individuals are not affiliated with the Deaf Community and function primarily within the "hearing world" in terms of family, friends, and work relationships. This is where many of us find we are between worlds. We don't really fit in the Deaf world because ASL is not our primary language. Furthermore, the culture and norms of the born deaf community are different from the culture and the norms of the hearing community that we are used to and have grown up with.

In the United States about one in every ten people has some degree of hearing loss, meaning anywhere between 22 and 28 million people have a hearing loss. The number of late-deafened people is increasing as the population becomes proportionately older. As the work force ages, these statistics have real implications for vocational rehabilitation programs.

There are a number of misconceptions about late deafness that can interfere with rehabilitation and service delivery efforts. I have had opportunities to go out into the corporate world and give inservices or workshops on deaf related issues. I start out by generally discussing different disabilities and then asking participants to think about which disability they would like to have the most! I ask persons to consider becoming deaf, becoming blind, being confined to a wheelchair, having a head injury or having cerebral palsy. More than half of the group always pick deafness as the disability to have. When I ask for reasons, the three usual ones are: "I can get a hearing aid; I can learn sign language; or I can learn how to lipread." It is important to remember that hearing aids do not restore the quality of normal hearing and wearing them is not the same as wearing glasses. The benefits of wearing aids are situation specific and depending on background noise and the
situation itself, the effectiveness of the hearing aid varies. It is amazing to me that I still come in contact with professionals who still believe the myth that a hearing aid "fixes" one's hearing loss.

People who are late-deafened do not automatically become good lipreaders. When people ask me if I can lipread, I usually respond, "What did you say?" Only 30 to 40 percent of the phonemes are visible on the lips. And added visual distractions like facial hair or lighting make this talent even more difficult.

Many professionals feel that the late-deafened community needs to learn sign language as a solution to the communication problems they face. But learning to communicate effectively in sign language requires a lot of time, effort, and motivation. Many individuals who are late-deafened are still connected to their hearing friends, family, and work. They have no one to sign with and have no motivation to learn sign language. For many people, it is also particularly difficult to learn later in life.

Many professionals in the rehabilitation field still feel the best indication of what is needed should be based on type and severity of loss. Again, other factors need to be considered when setting up services. The communication demands of a particular situation and the communication barriers in those situations must be taken into account. For example, a person who is late-deafened whose job requires very little or no spoken communications will likely experience less difficulty than a person with a lesser loss who has to communicate with people all day long in a variety of different situations.

An individual's adjustment to that hearing loss also has an effect on the situation. A person who has just experienced a sudden and extreme loss is going to find things more difficult than a person who has had time to adjust to the loss. One of my most difficult times was when my level of functioning changed. When I married and worked as a teacher, I had a hearing loss and wore hearing aids, but I functioned well. I went to movies, listened to
Carole King, talked on the phone to friends and family, participated in conversations and knew no sign language nor had any other assistive devices. After my second child was born, my function level changed. I no longer did well in conversations, could not go to movies, could not understand my kids, could not enjoy music, had to give up the telephone, and needed assistive devices like lights and captioning. I had to struggle with accepting how much things had changed. My family relationships changed because some of those things I shared with my husband when I could hear, we could no longer do together. I could no longer understand his jokes and could no longer understand the family. My family also had to adjust to many of the same things. It seemed we were all at different stages at different times. This was a time too when joining a support group was very valuable to me. I think this experience helped me understand many of the things that professionals need to know in order to work with late-deafened individuals. Services should not be based on severity and type of loss. Professionals need the big picture-- taking the functional level into consideration, the length of time the person has been deafened, and the adjustment and coping strategies, if any, the person actually utilizes.

With my social service background, I have noticed that many agencies assume the person that works with culturally Deaf consumers will also know how to work with late-deafened consumers. It's important to remember that although we sometimes share some of the same problems, we do have issues and problems that are unique to our group. Training can be given to the person that is working with late-deafened consumers so they understand these needs and issues. Setting up peer groups can fill a very needed void while this training transpires.

It is also important to understand the kinds of situations that can produce communication problems for late-deafened individuals so that when the services are provided they are accessible to the individual. Background noise can be a problem for some late-deafened individuals who wear aids or use other assistive devices. Visual distractions are another problem. When I was working at Progress Center, I had a very important meeting and I had
an interpreter I could not understand very well. I started to get nervous because I was not understanding much. The more nervous I became, the more I started to not pay attention and tune out. On top of that I was seated, so that I could see myself in a mirror while looking at the interpreter. So then I started to worry about how my hair looked. I finally realized I had to do something. I got up, switched everyone around so I had less visual distraction, and talked with the interpreter about slowing down and using more facial expressions. It was good I was able to do this but even afterwards I had to calm myself down a little bit and not think about the situation that had just happened. Many times too, people who cannot hear have gotten so used to not being able to understand things that they are a whiz at tuning out. They need to learn to listen again. By being aware of the potential problems a situation can cause, we can figure out ways to resolve some of them and help clients or consumers develop ways to cope with communication situations, especially if that client or consumer is not yet assertive enough to do it himself. In this situation there were a number of factors involved with my inability to understand what was going on. I didn't really understand the interpreter and the seating arrangement was initially not right for me. Other things can also have an affect. For late-deafened individuals who use realtime, or some other visual display, lighting and the size of the type on the visual display can be a problem. Failure to get the attention of the person before one starts to communicate can also throw the whole process off. All of these things can cause the late-deafened person to feel tired, stupid, or depressed. The individual may not even be aware of the connection between the hearing loss and these reactions.

When these communication problems arise, the late-deafened individual may respond in many ways. They may physically respond by becoming very tired and start to tune out or not pay attention. They may have increased muscle tension, lack of energy, and experience eye strain. Behaviorally they may bluff. Late-deafened individuals may also withdraw or avoid a situation, either by physically leaving or by tuning out as we talked about earlier. Another behavioral reaction might be attempting to control the conversation. Many late-deafened consumers I have worked with do this. I went through a stage where I did the same thing.
My thinking was if I talk all the time and control the conversation, then I don't really have to communicate. There is the fear of having to respond back to someone and making a mistake in the process.

Late-deafened consumers have emotional responses to breakdowns in communication as well. They can become anxious, depressed, angry, and even feel guilty. These are stages of the grief process most of us have gone through and perhaps, even continue to experience occasionally. I know from personal experience that these are all very normal feelings for a late-deafened individual. Ask my husband about the time I made dinner for his boss and his family. After a half an hour of communicating (or in my case trying to communicate), I locked myself in the bathroom and cried for an hour. There was the one Christmas where my entire family came to Oak Park from all over the country and I was so angry at not knowing what was going on that I stopped talking to them and went out to visit ALDA people instead. And there was a time too where I felt that I was 100% responsible for the communication problems in the family, at work, and even in the community. I would apologize for my inability to understand and could not ask for what I needed to help me understand, until much later.

By knowing these things, service providers can better understand the needs of late-deafened individuals and offer services that may help with the adjustment and coping with late deafness. Services such as confidence building, therapy, coping skills and support groups, relaxation training and biofeedback training, speech reading, assistive listening devices, or cochlear implants should be investigated with your client or consumer.

It is also important to be somewhat of a "communications specialist" for your consumers. Be able to analyze specific communication situations which affect the consumer. Check out CART and other visual display systems and know and understand how they work. Try different things with the consumers. My experience in working with late-deafened adults has shown me that many times the consumer does not know what is available or what is needed.
It is interesting to me that the majority of the late-deafened people I have worked with want a hearing person to listen to them when they are anxious or angry and going through the grief process. They need to talk. They don't want to fool around with technology or communicate back to a person if they have to type or use some other mode of communication. It is only later when they are more comfortable with themselves that they need and want the company of other late-deafened individuals for communication. I think though that even in the initial stages its very helpful to know there are people out there like yourself, even if you don't want to communicate with them just yet. Many late-deafened individuals have never even seen realtime captioning. Some are sitting at home still in the denial stage so they don't have closed captioning on their televisions or they don't have a TTY because they have no one to use it with. Late-deafened clients or consumers generally go to a social services agency because they have been referred by someone, a family member or friend who felt they needed services. Because of this, sometimes it is extremely difficult to work with this population group. Many times if they know you are there, they will come in, maybe drop out for awhile, and then return again. Usually when they do return it is because they have gone through some acceptance process and are more able to cope. I have also had the experience of seeing a late-deafened adult get shuffled around from one agency to the next looking for something and not getting whatever it is they need. Many individuals who do this are those who are not yet to the acceptance stage in the grief process and are still experiencing denial and anger.

To summarize I want to emphasize a few points:

When you are setting up a service delivery system for deafened adults, it is important to remember that generally this may be the very first kind of social service provider that they have been exposed to. Most have come from hearing world, a hearing job, and have hearing friends and family. The visit to your office itself may be overwhelming.
The deafened adult may still be experiencing stages of coping. Some never get beyond the anger stage or other stages of the grief process. For an individual losing the ability to hear, whether totally or partially, suddenly or progressively over time, there is a substantial loss of functioning to be accepted. This acceptance will not come all at once and may not come at all.

Find a way to communicate whether it be by realtime, sign language, a computer, blackboard or paper and pen. Communication is the key to establishing a good client consumer relationship.

Remember two words: "encouragement" and "patience". These words will help you work with late-deafened consumers or clients who may be suffering from low self-esteem, struggling with the feelings of not belonging anywhere, the loss itself, losing friends, losing communication with family and at the same time having no coping strategies.
The University of Arkansas Rehabilitation Research and Training Center for Persons who are Deaf or Hard of Hearing conducts a coordinated program of research and training focused on the employment of workers who are deaf or hard of hearing. This presentation describes results of two of the Centers's projects which are focused on job-seeking skills and workplace accommodations for persons who are deaf or hard of hearing. A national sample of persons who were late-deafened was surveyed to identify the workplace experiences of late-deafened persons. The information collected in the surveys was used to develop resource materials to assist persons who are late-deafened to succeed in the workplace.

The surveys were conducted in partnership with the Association of Late-deafened Adults (ALDA). Although the membership of ALDA may not be representative of all persons who are late-deafened, it is the largest organization of persons who are late-deafened in the United States. It is acknowledged that, by virtue of their membership in ALDA, individuals may represent a somewhat different group of late-deafened adults and are not necessarily representative of all late-deafened adults.

**Methodology**

ALDA members identified from the organization's national mailing list were contacted using a mail questionnaire. Of 818 initially identified members of ALDA, 374 members responded to our survey. The survey questionnaire used forced-choice and open-ended questions. The forced-choice items provided frequency data for many of the questions. The open-ended questions allowed respondents to describe specific problems or successes experienced during the job interview process or while obtaining appropriate accommodations on the job.
Characteristics of the Respondents

As expected, almost 75 percent of the members of ALDA primarily identified themselves as late-deafened. However, a significant percentage of respondents, almost 25 percent, identified themselves as hard of hearing. Sixty-three percent of ALDA respondents were women and the mean age was 50. Thus, most were of working age and likely to be in situations where their hearing loss may have effected their workplace adjustment and performance. In addition, it can be inferred from the survey respondents that ALDA members are a highly educated sample, composed mostly of persons with four year college degrees. In fact, a very high percentage of the respondents had graduate degrees (approximately 35%).

Most participants were currently working. For example, 52% were employed, 14% were unemployed, and 27% were not in the work force. Consistent with their educational status, most were employed in managerial and professional type occupations (55%). The second largest group worked in technical positions (31%). A very small percentage reported working in service professions. Additionally, all participants worked in companies that employed 15 or more employees, and thus, were subject to the protections of the ADA. For a more in-depth description of other characteristics of the membership, the reader is referred to a recent article in the ALDAnews (Boone & Scherich, 1996).

Job Seeking Experiences

The primary purpose of the Job Seeking project was to document experiences of the sample respondents with respect to job interviews and to use this information to develop job seeking skills training materials that were sensitive to these experiences. First, it was important to ensure that respondents felt they had a need for materials that would facilitate job interviewing. If respondents were not actively seeking work, one could infer little need for developing the materials. The bulk of the persons from our ALDA sample said they were looking for work (almost 95%). Curiously, most persons were currently working. Anecdotal information provides a potential explanation for this finding. One member of the ALDA group reported that "a lot of our people are losing hearing later on in life and that is forcing
them (even though they've had a successful career for a while) to look for work in different sectors."

Given this interpretation, one could infer that a different type of resource materials may be necessary. Most existing job seeking curricula are designed for people that have not been in the market before. Thus, you must start from scratch in terms of understanding how to do an application or understanding how an interview works. This may be unnecessary for many of these persons who have been in the market, previously looked for jobs, and succeeded in the interview. Such persons may need more of a fine tuning of their job seeking skills. Minimally, they must sort out job skills that are difficult to perform due to hearing loss, separate out those skills which are unaffected, and market these skills in the job interview.

Another possible explanation for the large numbers of persons looking for work is perhaps many simply desire a different line of work, regardless of changes in their hearing status. Perhaps their current job is becoming technologically obsolete due to changes in the labor market. Such persons must evaluate their current skills, and look for opportunities that make use of these skills in a different work sector. This requires a different approach to an interview. For these persons, transferrable skills are especially critical. One key to interview success is to describe your skills and experience and apply them to a different job sector.

Since 95% of the respondents indicated that they were looking for a job, we were also curious to determine if people had actually interviewed for jobs after they've experienced hearing loss. Ideally, such people would be in a position to describe and identify the problems they are experiencing, the barriers they are up against. The majority of respondents (76%) indicated they had interviewed after experiencing hearing loss. Respondents were asked to "globally" rate the impact of their hearing loss on their ability to perform in a job interview on a 5-point Likert scale from "No impact at all" to "A great deal." The mean ratings of the impact of their hearing loss on their ability to perform in a job interview was approximately 3, corresponding to "moderate impact."
Since the majority of ALDA members surveyed indicated that they were looking for work, we also asked people to tell us how skilled they thought they were in interviews. It is conceivable that there might be some differences in people's perceptions as a skilled interviewer compared to perceptions of being not quite as skilled. Most respondents reported moderate to high skill, with mean rating of 3.4. Despite these relatively high self perceptions, there is room for improvement, again arguing the need for training.

Methods Used to Communicate in the Interview

In order to manage the impression they create in the interview, it is critical for persons who are deaf or hard of hearing to communicate in the interview. In our work with sign language users, this means demonstrating how to use an interpreter since the odds are that most employers will not know or use sign language. Based upon the notion that hiring decisions are made in the initial 3 to 5 minutes of the interview, successful job candidates must demonstrate this skill very quickly in the interview situation. Since the majority of persons who are late-deafened often are non-signers, we were curious about the parallel situation with respect to other communication accommodations. These persons use a wide variety of communication alternatives. Some people primarily communicate through speechreading. Some people may try to use residual hearing, have an ALD, or a number of things. They might have an oral interpreter or they might sign. By far, most respondents said we try to "make do" using our residual hearing, hearing aids, and speechreading. However, some use more visible accommodations like ALD's or interpreters. These accommodations must be introduced appropriately early in the interview.

The final data collected in the job interview skills portion of the survey was related to the specific skills used in different parts of the interview. These questions were based on a curriculum developed at our Center for sign language users entitled GET-IT, Gaining Employment Through Interview Training (Johnson & Boone, 1990). This curriculum includes a number of lessons and criterion behaviors exhibited by skilled interviewees. We were curious to see if those same behaviors held up for people who are late-deafened or hard of
We asked respondents to look at the criterion behaviors from the GET-IT curriculum and to validate them from their perspective on two scales. First, we asked respondents to rate each skill in terms of its importance to interview success on a 1 to 5 scale where 5 is highly important. Second, we asked persons to rate how difficult these behaviors are to perform due to hearing loss. Results of these ratings are summarized in Table One which gives mean ratings for clusters of behaviors required in different steps of the interview process. Each step includes from 5 to 10 specific behaviors. You can see that from the perspective of late-deafened adults the criterion behaviors that are included were very important.

**Table 1**

**Steps in the Interview**

Mean (Standard Deviation) of Ratings

<table>
<thead>
<tr>
<th>Step</th>
<th>Importance</th>
<th>Difficulty</th>
</tr>
</thead>
<tbody>
<tr>
<td>Obtaining the Appointment</td>
<td>4.5(1.1)</td>
<td>2.9(1.5)</td>
</tr>
<tr>
<td>Meeting the Receptionist</td>
<td>3.9(1.3)</td>
<td>2.0(1.0)</td>
</tr>
<tr>
<td>Meeting the Interviewer</td>
<td>4.0(1.3)</td>
<td>2.4(1.3)</td>
</tr>
<tr>
<td>Answering Confidently</td>
<td>4.4(1.0)</td>
<td>1.9(1.2)</td>
</tr>
<tr>
<td>Offering Information</td>
<td>4.2(1.2)</td>
<td>2.5(1.4)</td>
</tr>
<tr>
<td>Asking for Information</td>
<td>4.1(1.2)</td>
<td>2.4(1.4)</td>
</tr>
<tr>
<td>Closing the Interview</td>
<td>4.2(1.2)</td>
<td>1.6(1.0)</td>
</tr>
</tbody>
</table>

Furthermore, respondents indicated that most behaviors are moderately difficult to perform, as evidenced by Mean ratings of around 2 on the 5 point scale. It was clear that the behaviors which were most difficult were the ones related to managing the communication situation. For example, respondents stated it is difficult to manage the communication situation or difficult to introduce my ALD. Since the ratings for most of these behaviors were moderately
difficult, one could hypothesize that people could benefit from some training on using these behaviors in the job interview.

Based on the results of the above surveys, *Gaining Employment Through Interview Training: A Curriculum for Job Seekers who are Hard of Hearing or Late-Deafened* (Boone & Berkay, 1996) was developed. Designed to provide individuals with guidelines and models of successful job interviews in an accessible format, the curriculum includes three primary components:

(a) manual of interview guidelines,
(b) workbook for self-study, and
(c) 75 minute captioned video of sample interviews.

The curriculum includes eight lessons which focus on the skills needed to succeed in job interviews. The initial six lessons focus on the primary components of a job interview and the behaviors that are exhibited by successful applicants in each of these component sections. Two additional lessons present proactive assertive strategies for problems related to poor interviewer behavior and overall examples of good interviews from start to finish. The video-based examples of interviews include persons applying for positions as a bank manager, a florist, a computer programmer, and an auto mechanic. The curriculum may be used in a group or on an individualized basis.

**Job Accommodation Experiences**

The primary objective of the job accommodations project was to identify the experiences of persons who are late-deafened or hard of hearing regarding provision of on-the-job accommodations. This information was then used to develop resource materials on accommodations. A literature review was conducted to identify problems in providing job accommodations to persons who were deaf or hard of hearing. Although there is a great deal of literature about job accommodations for persons who are deaf, there is very little literature on meeting the job accommodation needs of persons who are late-deafened or hard of hearing. The majority of what is known is anecdotal in nature, much of which was provided
by members of ALDA, the self-help group surveyed in the project. Since self-help groups presumably have greater access to information about accommodations and coping with hearing loss, we hoped that respondents from ALDA would be well informed about different accommodation options in the workplace, i.e., what works and what does not. The reality is that late-deafened consumers, as well as service providers and employers know when job accommodations might be appropriate, but are unaware of the full range of possible job accommodation options.

**Difficult Situations**

Review of both the literature and anecdotal information indicated that the most difficult situations for persons who are deaf, late-deafened, or hard of hearing are group and multi-speaker type situations. Furthermore, since most respondents were employed in "white collar" or "pink collar" jobs, it was hypothesized that verbal communication would be a more integral part of their job. When we surveyed ALDA members, we found that multiple speaker situations are the most problematic. The situations that are most difficult include work-related social functions, department meetings, in-service training, and socializing with co-workers. These situations are very important in one’s career development and affect whether (a) you know what is going on in your company or (b) you are part of the "office grapevine". Each of these situations are important for one's career, that is to say, they assist you to move up the corporate ladder, help you to be regarded to be part of the team, and help you be considered an important employee of that company. If you can't participate in these situations or when you do, you respond in a way that is not appropriate, a real problem in how you are perceived may arise. It is important to remember that all of these situations are seriously affected by communication problems.

Interestingly, the one situation for which respondents said that their hearing loss was not a serious factor was performance evaluations. However, in a survey of employers of persons who were deaf or hard of hearing, the employers indicated that the employee's hearing loss was a factor in performance evaluations. In fact, more than half of the employers surveyed
said hearing loss is a problem in performance evaluations with their employees who are deaf or hard of hearing. Therefore, even though consumers assert that it is not really a problem, it may be more of a problem than they realize. Workers who are deaf or hard of hearing are probably missing more than they are even aware of in that specific situation with their supervisor. For example, just missing that one word or that one little comment may make a difference in responding rightly or wrongly and can affect how your employer views you and the job you are doing.

**Devices**

Although the majority of situations identified as problematic were basically group or multi-speaker situations, the types of accommodations that are most often identified as being used were devices for one-on-one situations. For members of ALDA, the device most typically used on-the-job was TTYs and amplified phones. Despite the utility of these devices, they are not especially designed nor useful for most group situations. Very few ALDA respondents indicated that they used or had access on-the-job to ALDs that were appropriate for multi-speaker situations.

**Support Personnel**

For ALDA members, 38% indicated that they had some form of support personnel available on the job. Of those ALDA members who indicated that they had support personnel available, 51% indicated that interpreters were provided on-the-job and 20% received assistance from co-workers.

**Job Restructuring**

Very few ALDA respondents identified job restructuring as a provided accommodation. This is interesting because job restructuring is relatively inexpensive and often an easy way to resolve some communication problems. This is especially so if all you have to do is make a minor adjustment so that someone could do more of their job. For example, one respondent who worked as a laboratory technician in a hospital indicated she had some significant
problems working the 7 a.m. to 3 p.m. shift. She often had difficulty understanding what the doctor was saying on the phone. Most doctors, before rounds, tend to call the lab around 7-7:30 a.m. to get the information about their patients and help them determine if any changes in the course of treatment are necessary for their patients that day. Therefore, it can be a very busy and noisy place. She asked for restructuring as a modification. She said, "Can I change my work schedule?" Her schedule was changed to the 11 p.m. to 7 a.m. shift where it was quieter. There were fewer people in the lab and there were fewer doctors calling so she could provide that information to the doctor without getting frustrated, or the doctor's getting frustrated. This change in schedule allowed her to do the job. As she said on the questionnaire, if she hadn't done that "I would have had to quit my job." It was something that had to be done. She could with the restructuring now perform her job, and she had the added advantage of making more money for taking the graveyard shift.

**Bad Accommodations**

Respondents were also asked to evaluate the accommodations they had, i.e. "Do you have a bad accommodation?" The majority of ALDA respondents said the accommodations they presently had on the job did not work, were inappropriate, or for some reason just didn't do what they wanted them to do. We then asked, "would you like a different accommodation?" Overwhelming they said, "yes." Approximately 80% desired a different accommodation. Recall that the majority of accommodations provided were either amplified phones or TTYs. The reality is that these devices are not useful in the most difficult communication situations.

Unfortunately, when we asked them what other accommodation they would like, the majority said, "I don't know." From the data one can surmise that many late-deafened individuals are simply unaware of the range of accommodations available. Thus, they are unable to request the right ones. Instead, they use coping techniques that do not necessarily solve the communication problem at all. For example, meetings were identified as difficult situations for many respondents. When asked about the coping techniques that they most often used, many identified less than optimal strategies. Many indicated they did not attend; they did not
participate; they did not go; they did not ask; or they asked their boss to send a memo. They also often didn't socialize with their fellow employees and tended to work by themselves. If they did socialize with other employees, they tended to socialize with only people who were deaf or hard of hearing. They often would not socialize with the hearing employees. They would not go to meetings or go to social functions. For the most part, they would not do those things that we all know are essential for the boss to consider you as important and useful and therefore remember you. Being seen as being part of the company, a team member is important. When it comes to layoff or "downsizing" which is a new word for what happens in our corporate world, if the boss doesn't see the employee as important, if he or she doesn't see the employee as a member of the team, they are less likely to consider keeping him or her on. The reality is if the employee isn't seen as part of the "team" because they don't know what they need and are frustrated and don't feel they are getting anything out of this difficult situation, the worker is not projecting the type of attitude that says, "I am here; I am important to this business; I am a good employee; I want to be seen; and I want to be a part of this company." Instead, they stay in their office or work in their own little cubicle and never show their face. As a result, the hard of hearing or late-deafened employee often doesn't know what is going on or important changes in priorities within the company.

One of the reasons we decided on developing a curriculum is because we found that not only were workers unable to define what type of job accommodations they needed but had problems matching appropriate accommodations to difficult situations. When we asked what kinds of accommodations would work, most respondents couldn't even come up with an accommodation for that situation. Often they couldn't define the problem itself. Other than the situation itself such as "When I'm in groups or department meetings I have a big problem." But beyond that point for example, many had no idea what was causing problems in that situation or what would work within that situation.
Denied Accommodations
A final finding of interest was that 33% of the ALDA respondents had been denied an accommodation that they had requested. This is especially interesting because the survey was post ADA and in companies that theoretically were under the provision of this law.
Providing accommodations for persons who are deaf and hard of hearing other than interpreters, is relatively inexpensive. It is really not expensive to provide accommodations like an amplified phone, an FM system, or a conference FM system to sit in the middle of the table. Most of these are relatively inexpensive and only require a one time expense.
Interpreters are often the most expensive accommodation because of their recurrent cost. However, for the majority of this population, such accommodations were not frequently requested or provided. Considering the cost of most types of accommodations for persons who are deaf or hard of hearing, it was surprising that 33% of these requests were being denied. If you really look at it, the concept of undue hardship in the provision of accommodations is based on the concept of "will it cost too much given the company's financial status." And indeed, the bottom line in the provision of accommodations for most employers is "how much will it cost." But most job accommodations for persons who are deaf or hard of hearing are not expensive. In fact, under the ADA, employers are not required to provide the employee with the perfect (or most expensive) accommodation, only one that works.

In reality there may not even be the perfect accommodation for the employee. Each one of us is an individual and each person's hearing loss is different. It is important to remember that just because one has a hearing loss and it is the same configuration as someone else's, that does not mean that understanding of what is being said will also be the same. Hearing loss is so individualized, which in many respects makes it difficult to provide the "perfect" job accommodation. There is no perfect "cookbook" you can use. You can't say, if you have a 50 db loss then you can only use this hearing aid, or this ALD with that hearing aid will work. There are too many factors that get in the way. If the consumer doesn't know what to ask the employer for, then both the consumer and the employer are going into the decision
making process of identifying an appropriate on-the-job accommodations with little chance of success, resulting in frustration, significant frustration for both parties.

In order to assist with this process, the project has developed The Job Accommodations Training Curriculum for Persons who are Deaf or Hard of Hearing (Scherich & Berkay, 1996). This curriculum is presented in a computer-based learning format as well as in print format. The curriculum includes four training modules: Learning of Accommodations Needs, Identifying situations requiring accommodation, identifying and choosing potential accommodation options, and marketing accommodation requests. The curriculum may be used by employees who are deaf or hard of hearing and their employers.

- **Module I provides information regarding**
  (a) what is an accommodation and its purpose,
  (b) different accommodation categories with examples,
  (c) what is not an accommodation,
  (d) who benefits from an accommodation,
  (e) relevant legislation about accommodations,
  (f) general workplace situations that are difficult for persons who are deaf or hard of hearing, and
  (g) possible resources for further information or assistance.

- **Module II consists of the decision making curriculum.**

  This module uses a decision-tree format to help "break-down" the specific situation and identify possible appropriate accommodations.

- **Module III assists the employee and employer (or service provider) to choose the most appropriate accommodation from those identified in Module II.**

  This module helps the employee evaluate the positive and negative aspects of various possible accommodations and assist in choosing the "best" accommodation for the situation.

- **Module IV highlights the need for the employee to "market" the accommodation and thus, increase the possibility that the accommodation will be provided.
Module IV also deals with the possibility of a denied accommodation and how to respond and learn from that denied accommodation request.

References

This presentation discussed struggles, experiences and issues faced by individuals who are late-deafened as they adjust to hearing loss, a process that often occurs through trial and error and with limited assistance. Individuals who are late-deafened appear to adjust to issues related to deafness through a series of steps. Each step corresponds to an issue related to deafness; how this issue effects the individual, his/her family, and/or society; how deafness influences the adjustment process; and how the results effect the next step in the sequence.

As the individual who is late-deafened obtains information on issues related to deafness and skills to cope with hearing loss, he/she begins to explore effective communication methods. Communication strategies and new seating arrangements within various environments are discussed as an effective means to reduce stressors.

The rehabilitation process is reintroduced in the closing comments. The series of steps in adjusting to hearing loss are rearranged in order to assist professionals working with individuals who are late-deafened in providing services and assistance from the first moment these individuals learn about their specific hearing loss.

Figure 1 is made up of steps that represent a series of adjustments to hearing loss. People with a recent hearing loss will find themselves at or close to the top step. Others who have lost hearing some time ago will be further down the steps. Professionals will find that the series of steps represent the individual's progress with his/her rehabilitation process.

HEARING LOSS:
The loss of hearing may be gradual and unnoticed; progressive and relentless; sudden and unknown; or known, but denied. Regardless of how or why deafness occurs, it unravels the world of hearing and communication as it was once known. The response to the unraveling
will depend on the support and changes which occur within the individual's environment. Whatever the reason or the support level, individuals seek information and answers regarding their specific hearing loss.

The circumstances under which individuals seek answers may determine the success with which they adjust to and cope with hearing loss. Consider these examples. If an individual seeks to determine the extent of his/her hearing loss to satisfy nagging family members or significant others, the adjustment to the loss may be less than satisfactory or slow at best. On the other hand, if the individual seeks answers regarding his/her hearing loss with support and understanding from significant others, the adjustment to hearing loss begins more favorably.

AMPLIFICATION SYSTEMS:
Based on an initial hearing test, individuals may obtain information regarding their specific hearing loss. The amplification system most often prescribed is a hearing aid(s). At this point, many individuals will purchase a hearing aid(s). Others will not purchase an aid(s) because they cannot afford them. Service providers assist people that qualify in obtaining an aid(s), even though many individuals will not benefit from an aid(s) due to the severity or the specific type of hearing loss.

The hearing aid(s) seems adequate at the time of purchase. However, satisfaction with the aid(s) may begin to deteriorate as the individual realizes the system does not work the same as "normal" hearing. The individual focuses on the aid as a means to correct his/her specific hearing loss to a "normal" state, similar to the way glasses correct one's vision. Adjustment to wearing an aid(s) and coping with environmental sounds becomes unmanageable. It becomes impossible for the individual to separate out background sounds from conversational speech. Conversation is often unclear, broken into small increments and laboring. Trying to cope with sounds never heard, forgotten, or unrecognizable can become unbearable. As a result, the individual becomes dissatisfied, angry and disillusioned because the amplification system is not what he/she thought it would be. "Normalcy" of sound and communication is
never the same and is gone forever. The adjustment period of learning and using the aid(s) is short lived.

COMMUNICATION CHANGES

FEELINGS & EMOTIONS:

Hearing people listen to idle chatter, lectures, sermons, telephone conversation, radio or television programs without much effort. As hearing diminishes, listening takes more concentration, physical and emotional energies, and staying power or stamina. The individual who is late-deafened may begin to feel diminishing power and control over his/her listening situation. The individual begins to rely on others to monitor conversation and answer questions. The communication world is not the same. As a result, changes in the way to communicate begin to occur.

At the beginning of hearing loss, there is a considerable amount of notewriting. This is a method to keep the individual who is late-deafened informed. Notewriting is labor intensive because, as English speaking and writing individuals, we tend to write in complete and long drawn out sentences. This is exhausting and frustrating to everyone. It often leads the individual who is late-deafened to become more angry and frustrated as he/she wants the person to get to the point. Often, there are long periods of silence as the communication is written, read and responded to. Because notewriting tends to be long and cumbersome, resentment may build and lead to a great deal of hostility, anger, frustration, agitation and other negative feelings and emotions. The individual who is late-deafened becomes angry because family members have not given the precise information requested of them. Family members feel alienated as they have tried their best to give clear and detailed information. When asked to explain the reasons for his/her negative reaction to written communication and content, the answer frequently given is "they should know what I want; they just don't care." The need to repeat what has been said is one of the biggest areas of frustration and anger expressed by family members. When asked to repeat, there is a tendency to become angry or agitated. The thought of having to repeat the entire message or conversation infuriates them.
They often wonder why they were not informed that they were not understood and why the
person waits until they have completed to ask them to repeat. They find this task exhausting.
This results in an unwillingness to repeat for the second or third time, and as this occurs
again and again, conversational exchanges cease.

Communication changes begin to affect everyone. Individuals who are late-deafened, their
family, and friends begin to experience more stress and negative feelings and emotions
toward each other.

Negative feelings and/or emotions may lead to or create isolation and withdrawal. Feelings
and emotions are often repressed and avoided which can lead to depression because the
individual feels left out or unimportant. Depression is a complicated withdrawal process
which can last a long time. The feelings of being a nuisance or feeling virtually unwanted
can occur. Anger may result as he/she struggles to understand "why has this happened to
me?" and the limitations imposed as a result of the hearing loss. Anger towards family or
friends builds and often becomes explosive. There is the feeling that family and friends are
unwilling to adjust to new communication needs and/or it takes too much energy to
communicate effectively.

Some of the most common communication themes documented from individuals who are late-
deafened are: 1) "People don't understand that I don't hear in the way that I did before. My
communication is not the same and it doesn't seem to matter to them," 2) "I get sick of telling
them over and over that I don't understand what they are saying;" and 3) "They just don't
want to take time to make communication understood."

For the person who is late-deafened and their significant others, communication has changed.
What is described as "indifference" causes the person who is late-deafened to become
extremely angry and bitter. As resentment towards family and friends increases, there appears
to be a stand off or a stalemate. The person who is late-deafened gives up, stops communicating, withdraws, and takes a back seat to the world around them.

HEARING WORLD:
In the hearing world, communication is a key component. Most of what is accomplished in our daily life requires communication. We live in a fast talking, fast moving culture. Time is often critical and getting points across requires the easiest and quickest route possible. These routes are speech and listening. Taking time to slow down and facilitate clear, concise communication seems foreign or beyond the realm of the norm.

The individual who is late-deafened is now faced with new communication challenges he/she never expected to encounter. For example, when hearing people are told "I am hearing impaired and I don't understand", hearing people often suddenly start to shout and seem nervous. This reaction occurs because they do not know how to help the individual who is late-deafened with his/her communication. If hearing people are asked to change their communication style by slowing down, speaking clearly, looking directly at the individual when talking, or other requests, they often do not have nor want to take the time. The hearing person may find it difficult to believe that the individual truly does not hear. This is partly due to the fact that many individuals who are late-deafened have excellent verbal skills and are fairly successful speechreaders.

In many respects, the nature of the hearing world forces the individual who is late-deafened to withdraw. This occurs because the hearing world expects everyone to function as hearing people. As a result, the hearing world puts constraints on communicating effectively.

ADJUSTMENT COUNSELING
Communicating in public places is no longer comfortable and inviting as when the individual functioned as a hearing person. Family or social events are less appealing when conversation or chit-chat requires more energy and effort. Constantly reminding hearing people to speak
up, slow down, face them, or say things over and over again may begin to be grueling. For example: "My family and friends continue to talk to me as if I am a hearing person. I can't seem to make them understand that I don't hear the way I did before." As a result, the individual who is late-deafened becomes passive and allows others to do the talking for them.

Individuals who are late-deafened are bound to the hearing world through their memories as "hearing people." However, communication changes have hurled them forward into an unknown world. Communication breaks down and an amplification system is not sufficient. Hearing people do not understand the struggles. The person who is late-deafened may begin to question whether he/she has lost their grip on reality.

Adjusting to and coping with feelings and emotions related to hearing loss can become overwhelming. This may result in a loss of self-esteem and self-identity. Hearing loss means less enjoyment from and frequency of going to social gatherings. This may lead to withdrawal or isolation. At this point, the impact of hearing loss on the individual is critical.

To find answers, the search for outside help begins. This help is often provided by such professionals as social workers, counselors, or clergy. The results can be less than satisfactory because these professionals, although very skilled and credible, often do not understand issues related to deafness. The very communication barrier the individual who is hearing impaired needs counseling for is likely to occur in the counseling sessions. Although it is not always possible to find professionals who have a background in deafness, there are ways to assist with the adjustment process.

Adjustment counseling by the appropriate professional is a means to provide individuals who are late-deafened and their families with support and knowledge related to hearing loss. For many people there is a stigma attached to hearing loss. When people notice that an individual is wearing a hearing aid, often the individual is thought of as being senile. In other words, the individual who has lost his/her hearing has somehow lost his/her mind.
Adjusting to hearing loss not only means adjusting to his/her particular loss but society's stigma.

**Individual vs Group vs Peer Counseling:**

The most successful counseling approach to use depends on the individual's needs and situation. It may also depend on whether a support group exists in the geographical area.

**Individual** counseling provides the person who is late-deafened with a means to work through specific grief, needs and issues related to deafness. Anger, frustration and other emotions can be explored and expressed in a safe environment without outside stressors. Individual counseling is based on many counseling theories and techniques. Oftentimes individuals who have lost hearing have difficulty separating out issues related to hearing loss from those related to other life stressors. Individual counseling gives an opportunity to work through all aspects to determine if the issues being presented are related to hearing loss or other issues.

**Group** counseling would provide the individual a means to work on deafness issues with others who are also late-deafened. Therefore, group counseling does not focus on the individual and his/her specific needs or issues but the entire group. This type of counseling exposes individuals to a variety of ways to work through situations by asking what others have done in similar situations. It provides support and understanding from others who have been in similar situations. The group can provide a great deal of assistance in problem solving such situations. The group shares understanding, grief, pain, loneliness, and struggles.

**Peer** counseling is a service provided by a fellow individual who is late-deafened. This individual is a role model. The peer has been through the adjustment process and is able to cope in spite of having experienced similar problems. Individuals who have "made it" often know how to provide support, identify key problems, and can gain the confidence of individuals who are newly late-deafened.
ASSISTIVE DEVICES
Regardless of the type of counseling, the need for additional communication alternatives begins to emerge. Learning about assistive devices is a constructive means to address the problem of communication breakdowns. Assistive devices may be introduced more generically at this time, and can be explored in more depth as the individual becomes more accepting of the hearing loss and consideration of new communication methods. Devices, even in broad categories, can be an important new tool for coping.

Choosing Communication Methods:
Because the hearing world often has no idea how to accommodate communication disabilities, individuals who are late-deafened are left with the task of finding alternate communication strategies and educating others on how to use these alternatives. A number of alternatives can be explored.

Speechreading is one communication method. Some individuals find this task to be relatively easy, while others struggle. Speechreading also has its limitations. Lighting, background noise, facial makeup, or hair, can make speechreading very difficult.

Sign language is another method of communication. For older people, sign language requires a great deal of repetition and mental concentration. Many older adults who are late-deafened find signing excruciating due to arthritis. However, learning the manual alphabet and teaching this to others provides a means to fill in missed or misunderstood conversation or words.

Total communication is a conglomerate of communication methods. This may include speechreading, sign language, amplification systems, pen and paper, assistive devices, and other modes to make communication successful. The individual who is late-deafened can determine the best methods through trial and error.
A cochlear implant may also be helpful. As technology and medicine continue to work together, new and interesting possibilities for the future emerge. Studies have shown that some people have had great success with cochlear implants while others are not as successful or not eligible due to their specific hearing loss.

Choosing the Right Assistive Devices:
As needs become more clearly defined, the search for alternative ways to improve communication begins. The individual begins to learn about alternative devices because the hearing aid(s) has not provided all the communication satisfaction hoped and searched for. The need for better communication motivates the individual who is late-deafened to overcome the core belief that technology is too tough. The stigma attached to technology as being complicated, cumbersome, and confusing diminishes.

There are devices to assist with telephone conversations (amplified receivers, TTY), devices to assist with communication in large groups (personal listening system, loop system, FM or infrared system), devices to assist with stereo or television volume (infrared system) or captioning possibilities. There are also devices to alert one when sounds are in the environment. The technology is rapidly changing and new products abound. This is merely an overview of the array of technology to be explored.

NEW FEELINGS & EMOTIONS
COMMUNICATION STRATEGIES:
Despite the difficulty of hearing loss, the individual who is late-deafened may begin to realize that hearing loss does not mean the end of communication. As the individual adjusts to deafness, new feelings and emotions surface and adjusted relationships with family and friends develop. The feelings of depression, withdrawal, anger, agitation and loneliness addressed in counseling may be replaced with feelings of optimism, confidence, and inspiration. Through adjustment counseling, the individual who is late-deafened deals with change and gains renewed hope. Adjustment takes time, commitment and willingness to
move forward. The individual who is late-deafened may begin to emerge with workable communication and coping strategies. Although deafness is a part of the individual's life, accepting and excelling beyond the situation makes all the difference.

Communication Strategies:
With new found optimism and knowledge comes the ability to communicate effectively. Some of the communication strategies often discussed include facing the person, slowing down, avoiding exaggerated mouth movements, chewing on something and talking at the same time, rephrasing the problematic statement, and substituting a word with similar meaning for the difficult word. Other effective means to communication include:

1. Educate, educate, educate. Individuals who are late-deafened will need to provide the hearing world with a never-ending reminder of what needs to be part of the communication process. This reminder and education process is ongoing. The hearing world cares, but does not know how to approach communication barriers. There is fear or uncertainty primarily because hearing people do not understand the impact that deafness has on individuals.

2. When asking someone to repeat what was said, provide the individual with the part of the conversation, topic or statement that was not understood. When asking a person to repeat what was said, there is an automatic assumption to go back to the beginning and start all over again. Think of an actor who says lines and then is asked to repeat them with more feeling. This can cause great distress as the actor feels that the best performance was already given. The actor may repeat lines with less flare and more strain. After a few times of correction in repeating the specific request, the individual soon learns to give information in the correct way.

3. When asking someone to write a note, ask for specific information such as where, what, when, how, and who. This creates less anxiety and stress when specific information is known.
4. Clearly state your needs and stick to them.

5. Be willing to give up favorite places to sit in order to accomplish better communication. Explore new arrangements throughout the home. New seating arrangements and lighting can provide better or more successful involvement with communication.

The title of the presentation, "This is Now My Favorite Chair" is now more understandable. Individuals who are late-deafened often speak about the seating arrangements within their homes. Hearing the television, stereo, conversations or other sounds within their environment is difficult. Through discussing the layout and picture of the room, it is soon acknowledged that they are not in the best location to have successful communication. They realize their favorite chair may not be the best one for conversation. As a result, they explore new alternative seating arrangements (see Figure 2).

It is not unusual for family members to say, "You never sit here. What are you doing there?" The best answer is, "This is now my favorite chair." One example of where communication most often occurs in the home is the kitchen. The individual's current location may not be good as the freezer and refrigerator generate a great deal of noise. Rearranging the kitchen table seems to be a better choice or sitting with one's back to the kitchen window may also be a good choice.

Final Comments:
The current rehabilitation process (Figure 1) shows a series of steps individuals who are late-deafened experience as they struggle to adjust to hearing loss. Adjustment often occurs through trial and error and with limited assistance. The suggested rehabilitation process (Figure 2) shows a series of steps of adjusting from the moment individuals learn about their specific hearing loss.
Adjustment means more than obtaining an amplification system. Adjustment means learning about the specific features of an aid or why it is appropriate for the individual. Individuals who are late-deafened may obtain a more satisfactory adjustment to an amplification system if professionals explain the positive and negative features of the aid(s). Providing the individual with an explanation as to the reason sounds will seem different than when he/she was a hearing person would also be beneficial. Giving individuals more hands on information regarding the use and care of the aid is important too. Under the current rehabilitation process, professionals do not often provide this additional information or "hands on" training. As a result, hearing aids are often presented as the only needed step to better hearing and communicating.

Addressing emotional issues related to deafness earlier in the rehabilitation process can assist, limit or prevent stressors faced by individuals who are late-deafened. Discussing hearing loss, amplification systems, feelings and emotions, stressors and ways to cope with this unknown world will reduce anxiety, anger and other negative feelings and emotions before they become a burden.

Determining the best counseling method will depend on the individual's needs and issues. One counseling method found to be very effective has a group counseling component that involves persons who are late-deafened, and their significant others. This provides everyone opportunities to learn about issues related to deafness, how others cope and what strategies they use to communicate in various situations. They find ways to assist each other through this new and unknown world of hearing loss.

When amplification systems (hearing aid) are purchased, assistive devices need to be explored and explained and appropriate information provided. When making device choices, individuals benefit from professional assistance. Without knowledge and assistance, devices purchased are often ones advertised on television or junk mail. This causes additional stress as often these devices can only be used a short time or never used because they are
inadequate or not appropriate. Providing consultation on assistive devices prior to purchase reduces the chances of obtaining inappropriate equipment and reduces stressors.

Discussing alternative communication methods provides the individual who is late-deafened with additional ways to cope with and adjust to day-to-day problems. Alternative methods allow individuals who are late-deafened to have more control over their communication environment. The individual isolates himself or withdraws without ever leaving the chair he/she is sitting in. In other words, others begin to compensate for the individual who is late-deafened. They become the spokesperson or talk as if the individual were not in the room, let alone sitting at the same table. Conversation tends to occur all around the individual who is late-deafened as though he/she were nonexistent. The individual who is withdrawn allows conversation to continue without interruption or trying to understand what is being said.

One strategy that is useful during the initial meeting or assessment is to ask the person providing the information to allow the individual who is late-deafened to answer for himself/herself. Explain how the hearing person's assistance is appreciated but the individual with the hearing loss needs to answer the questions. When given an opportunity to answer for themselves, the individual who is late-deafened has a great deal of information to provide. As he/she becomes more comfortable, the individual takes control of the conversation because he/she feels important and what is said has merit. Further observation shows that the spokesperson is often surprised by the involvement of the person who is late-deafened.

Adjusting to deafness requires acceptance of one's hearing loss and the limitations imposed by that loss. Hearing loss also requires acceptance and understanding from family, friends and society. Misunderstanding the intent of the hearing person can cause the individual to stop trying to communicate with the hearing world and may result in isolation and/or withdrawal. What is often forgotten about hearing loss is the issue of time. Adjusting to hearing loss and communication changes takes additional time. There is often a breakdown in the time allotted and the way communication is transmitted. Hearing people often feel they have to
yell or make absurd gestures to convey their message. Often the individual who is late-deafened interprets this communication as anger or hostility towards them. Exaggerated mouth movements and gestures can cause the individual to become depressed, angry, and/or frustrated.

Being better prepared earlier in the rehabilitation process can slow down or eliminate barriers related to communication. Learning to adjust to communication barriers early can provide the tools needed to educate self and others regarding easier and more effective ways to communicate. In this way individuals who are late-deafened don't misinterpret the communicated dialogue.

More positive feelings and emotions can be expressed at the outcome because he/she has been provided with effective professional services from the very start of hearing loss. More informed choices may occur due to professional assistance regarding amplification systems and assistive devices. The individual's feelings and emotions are dealt with through adjustment counseling. New communication methods are explored to provide ways to cope with the hearing world. Effective communication strategies are probed to continue in the hearing world.
Figure 1: Current Rehabilitation System  
Series of Steps of Adjusting to Hearing Loss

- New Feelings & Emotions
- Communication Strategies
- Choosing Assistive Devices
- Adjustment Counseling
- Hearing World
- Communication Changes
  - Feelings & Emotions
- Amplification Systems
- Hearing Loss
Figure 3  Rehabilitation System
Series of Steps of Adjusting to Hearing Loss
The ALDA Leaders Rap Group provided an informal forum for group and chapter leaders to share experiences and ideas related to leading ALDA groups. A dozen leaders met with Chapter Coordinator/Leader Letter editor Nancy Kingsley and Board/Chapter Liaison Kathy Schlueter (a member-at-large of the ALDA Board and president of ALDA-Freeport) to discuss issues and provide feedback and suggestions. Discussion focused on topics such as defining ALDA's intended target population, providing transportation to meetings, dealing with subjects unrelated to deafness, selecting suitable times and events for meetings, and ways the Board and ALDA groups could assist each other.

Who is ALDA for? Leaders were initially asked for input regarding an issue raised in a communication from Judy Tingley, an ALDA Board member who was recently involved in starting a new ALDA group. She wrote that people who attended the first meeting of her group had indicated uncertainty about their suitability for ALDA and had made such comments as "Was I too young when I became deaf to be eligible for ALDA?" "Do I hear too much?" "I was born deaf but raised orally and live pretty much in the hearing world. But feel isolated, can I join ALDA?" "I have a cochlear implant and I don't want anyone to think less of me for it."

Rap Group attendees were asked for suggestions as to how to ensure that potential members understand who ALDA is for. One leader responded, "I lost my hearing at a year old. I'm an oralist and I grew up in the hearing world. So I think it should be clarified that ALDA is for people who lost their hearing after birth."

A leader then observed, "I became deaf at the age of six. When I first became interested in ALDA, I thought most people were much older than me when they became deaf. It's
important for people to know that ALDA is for everyone who lacks hearing, but uses English as their main form of communication. Our philosophy is that no matter what your background is, you can fit into our group. We want to be inclusive, not exclusive."

Another person remarked, "I was born hard of hearing. I was raised orally in a hearing environment. My parents, school, everyone tried to make me hearing. It wasn't until several years ago that I accepted the philosophy that I'm not with the hearing world. But I'm not with the culturally deaf, so where do I fit in? I feel that ALDA is perfect for those people who are in what we call the twilight zone, those who are not hearing and not culturally deaf."

The concluding comment on this topic was made by a leader who stressed the importance of finding a place where one feels comfortable, regardless of the exact status of one's hearing loss: "I was born hard of hearing, but it was when I found ALDA that I found my family."

**Members needing transportation.** Leaders were asked to share any other issues that affected their groups, and one person responded, "I'm finding people that don't have a way to get to the meeting. They keep asking me if I know other people who could give them a ride. And because they don't have a ride, they don't come. So how do I solve a problem like that?"

Another ALDA group leader added, "I have a friend who has a problem getting to meetings. She has no transportation. The people in ALDA know this, yet nobody seems to help her. She desperately wants to go to meetings. How can we get people to show more concern for her?"

In response, a leader suggested, "If there are many people in another area, then maybe you can move the meeting or have an event or party in a different area for once and see what the response is. If that doesn't work, then you can still have contact with those people by phone or computer. Maybe later you'll get more people in the area and they can go together."
Another possible solution was offered by a leader who said that the deaf and hearing service provider(s) in her area indicated that they might be able to provide a van to pick people up and bring them to the meetings.

Discussing issues unrelated to deafness. A leader asked for assistance in dealing with a member who wanted to discuss life issues not related to deafness. A respondent suggested setting time limits for speaking. If the topic raised is irrelevant to the purposes of ALDA, the leader should break in and indicate the need to stick to the subject of hearing loss. Another leader commented, "The meeting is for deaf people. Other concerns or subjects should not be discussed, unless it is agreed upon by the people in charge."

Selecting meeting times and events. A leader stated, "Some people don't like to go out at night for meetings and some can't go out during the day. How do you plan a variety of activities so that people that have different schedules and interests can merge?"

Nancy observed, "One thing my group has found very successful is gatherings in people's homes, because it doesn't matter if one person likes to bowl and another likes to canoe. Everybody gets to do the thing that people really want most, which is to interact with one another. I know from some of the other groups that have contacted me that it's not always easy to find an activity that attracts enough interest. But the focus really is on people more than on the activity."

A leader added that in his group, some activities are held in the morning, some in the afternoon, and some at night. "Some are parties, some are educational [presentations], some are [recreational activities, such as] bowling. We try to mix them up to get different types of people to come. But the most popular ones are the restaurant functions. At our New Year's brunch on the Sunday after New Year's, we get thirty to forty people. At our annual birthday party, which is in the evening, we get thirty to forty people. With something like bowling, we get five. For apple-picking, we got eight."
Another person noted, "The only problem with going to restaurants is that sometimes they get kind of expensive. You might lose people because of that. Nonetheless, it's still a good way to socialize, sit around the dinner table and enjoy a good meal."

A leader commented, "We have our meetings at 1:30 one Saturday a month and then we have a social at 3:30 until however late people want to stay. That means they can be there for a while before it gets dark and have time to drive home. We try to vary the activities to fit everybody. But you can't please everybody every time because we have different interests, and the social part is the important thing here."

Another leader added, "Many times we have potluck and we find that to be really a good way of socializing. Many people come and they stay for a long time. They talk about everything. And it's cheap."

**Communication between the Board and ALDA groups.** Kathy then discussed several matters affecting ALDA groups and chapters. Comments on some chapter renewal forms showed that there was insufficient communication between the national level and the chapter/group level. All mail needs to be sent to ALDA's Virginia address, because the forwarding orders of previous ALDA addresses have expired. Leaders were advised to discontinue use of old forms containing expired ALDA addresses.

**ALDA brochures.** Leaders have requested copies of the ALDA brochure. Five thousand brochures were recently printed and distributed. After the selection of a new ALDA logo, redesigned and updated brochures will be printed and made available to leaders.

**Information requested from ALDA groups.** Kathy asked for a list of each ALDA group's local membership in order to be able to inform them about the national ALDA organization. Chapters and groups were also asked to send copies of any publications from their group so ALDA National will know what is going on in their area and the information can be included
in the ALDA Biz, ALDA News, or Leader Letter. Kathy and Nancy asked leaders to keep them informed of any changes of leadership so mailings reach the appropriate person, and Nancy reminded leaders that submissions are always desired for the Leader Letter.
This workshop is concerned with getting access to the church of our choice. Churches have no legal obligation to be accessible to people with disabilities. For those of us who are deaf, it is difficult to visit a number of churches to see which one we might wish to join. Having made a choice, it is also difficult to ensure access thereafter, not only for the worship services but the other activities that are important in the life of the church community. The two of us (presenters) will address our own experience(s) in settling on and in a church and how we worked to obtain the access we needed. People in the audience are encouraged to also participate in the discussion.

JUDY: We are not concerned here with any specific denomination or with what people believe but I will just mention at the outset that Robin is a member of the Episcopal Church and I am a member of the Unitarian Church. Our focus here is on the fact that access to any church of any kind is not covered by the Americans with Disabilities Act (ADA). We have no way to "throw the book" at them and say "you have to be accessible." How do we get access to whatever church we may want to attend?

ROBIN: I was not raised in a church environment, but when I moved to Georgia, I joined a Methodist church. There was a wonderful woman there and she was committed to anyone else who wanted to be involved in the church. She felt everyone should be able to go to whatever events they wanted. She really spoiled me because any time that church had an activity she asked if I wanted to go. I'd say "yes" and she'd find an interpreter for me. I don't know how she managed this because the church only paid about $10 per event. After several years, I was not really satisfied with that church and decided to change to the

This workshop encouraged interactive discussion. For greater clarity, however, the input from the audience is placed after the prepared comments from the presenters.
Episcopal Church. There were no other deaf people attending. I wanted to really be involved and this is very, very hard. It is still sometimes hard for my church to understand this. None of my interpreters are Episcopalian. I steal them from other churches! The church now pays $25 per Sunday and may add another $25 if there is a special event afterwards. It isn't much but at least ensures that we have a professional interpreter.

There are many ways I have tried to show the church I want to be involved. I think because of our disabilities, they have the impression we need help and they can see us as "victims". They don't see us as a member who has responsibility at that church. So it's been up to me to really force that issue with them. I make my pledges and I take on roles. But again, I have to force that with them. There are still some problems coordinating the interpreting services. Since my work during the week is coordinating interpreting services, I told my priest I would do anything for this church but will not look for an interpreter for myself. We now have another person do that. One of our fundraisers is a silent auction where members donate things or time that can be auctioned off. One of the things I did that I think was a little bit creative was to offer three sign language classes. I didn't even know if anyone would bid on that but there was some hot competition for these private lessons. It was a lot of fun and a way to meet someone in the church on a one-to-one basis!

It is still not perfect. The church still puts a lot of responsibility on me. No one asks me if I want to attend some event; I have to say "I heard there will be a party next week and I'd like to have an interpreter there." They still kind of assume that the interpreter will come with me or that I will find someone, my twin or somebody who follows me everywhere! I still have to do a lot of self-advocacy.

I find it almost insulting that the church seems to feel that one deaf person is not enough. To me, one is enough. If I need it, that's enough! But I still get pressure from the church: to bring my deaf friends to church. I said "Fine, there's a party next Friday night at the deaf club, do you want to come with me? You can get to know them yourself." They reply "oh,
no, I'm busy." Just because you put an interpreter there and a notice in a deaf community publication it doesn't mean everyone is going to come all of a sudden. They need to know the people at the church first before they are willing to come into a group of strangers.

Also, we talk about inviting different deaf people to one service but that really complicates how it's going to be accessible. At my church, if culturally deaf people suddenly started attending we'd have a problem because the interpreters are not skilled enough in ASL. If we had an ASL interpreter, I would miss a little bit of it! I understand ASL, but I still want the sermon in English.

Finally, in the Episcopal church, you have to have a relationship with the priest. I have been fortunate that I can lipread my priest pretty well because it would be difficult if I had to bring an interpreter. My priest has been really wonderful and I meet with him regularly so he gets to know me as a person. He uses the relay service to call me and he's very comfortable with that, but it has taken a long time and we aren't finished yet.

I have been going to that church for five years now so if you are struggling to get things set up in your church or temple, it is not easy. It is very frustrating. There have been times when I have wondered why church should be so hard for me. I hear the priests or ministers fuss about other people who don't show up on Sunday and stay in bed, and I think to myself "I'm here but I still have to work to be sure it's accessible!"

I had to ask myself how flexible I could be regarding the skill of the interpreter. I have "raised" several interpreting students at that church. Unfortunately, I have raised them so well, they have gone elsewhere to work where they are paid more! This sounds awful to say but I kind of try at my church to have a good interpreter one week and a so-so interpreter the next week. When you have a trainee, you have to teach them some of the signs. I enjoy teaching but on Sundays I really would rather kind of sit back and relax. But that's part of
my flexibility. I understand that these interpreters are not going to be like my staff
interpreters at work.

**JUDY:** For me, this was a very long process. I come from a family that is active in the
Presbyterian church, and my daughter is in the ministry herself. But that denomination has
not really provided much in the way of special services for people who are deaf. And I had
been totally inactive for many years in any kind of church. The one thing I knew was that if
I did go to any church, it would be a hearing church with an interpreter. I had tried churches
for deaf people but I grew up hearing and that was an important part of my life that I wanted
to continue.

I always felt left out because I was the only one in my family without a church affiliation. I
also felt stymied by the fact that it is not possible to go and visit different churches to see
which one I might want to settle on as my home church. You can't just drop in. When
you're deaf, you can't be impulsive and do things spontaneously. You have to plan everything
ahead of time and it can take five hours of work to get one hour of interpreting! So that in
itself was enough to deter me from even trying.

What I really wanted was a church that offered me an opportunity for fellowship. I had just
moved to Madison and did not know many people and I thought a church whose beliefs I
shared might be a way to meet people. Oddly enough, I stumbled on my church because it
was designed by Frank Lloyd Wright and I am very interested in architecture. I had stopped
in for that reason and ran into the minister. He has a heavy beard and mustache and I'm not
able to lipread him very well. He mentioned that a member of the church is an interpreter so
I asked if it would be possible to provide an interpreter for a Sunday service. This was
arranged and it was almost a sublime experience. **THIS is MY church. THIS is where I fit!**
How do you get interpreters from then on? The minister said that the budget is a problem and I know that is legitimate. He said perhaps they could interpret once a month and even though I knew that would never be enough, I said okay because you have to start some place.

He also said I would need to promote this and get the word out to the deaf community so more deaf people will come. Well, remember, I had just moved to this town and I did not know very many people there and I really did not want that responsibility.

By this time I was beginning to question my stamina to put up with this struggle. I thought it was a contradiction that the church where one might find some inner peace would cause so much fight! Some correspondence between the minister and I ensued and it helped get us to the point where today the church has an "Accessibility Fund", we have an interpreter every Sunday and for the other activities that I participate in. The one thing I did in regard to outreach was post an announcement on the Wisconsin Association for the Deaf electronic mail bulletin board. This goes to 100 e-mail addresses but no one else has come yet.

There is a cycle to my church's activities that follows the school year. I found just this fall that a lot of things were starting up so I've joined a monthly circle supper (the composition of the group changes each month) and I've taken a 4-week orientation course for new members, all with an interpreter. In this way, I'm slowly getting acquainted with people and I think some will appreciate that accessibility fund and contribute to it as I have.

I have spent a lot of my professional life taking on that educational process in other areas and I just needed one area in my life where I didn't have to struggle for access. This topic was proposed in the middle of my struggle when I was starting to question whether it was worth it. However since raising the topic, we've achieved a satisfactory solution at my church. Was it worth the struggle? Yes! But it was not easy. I chose to teach only one person and that was the minister. The rest of the church will just learn as we go along. I am still the only deaf person attending.
I know I made it hard on myself by being inflexible about just which church I wanted to attend. I really like the Parish Minister and would have been willing to drive much farther, if necessary, to attend.

I would not minimize the strength required to deal with this. I had to ask myself for a long time, am I strong enough to deal with it? Why not just take the easy route and join a deaf church? But I felt so strongly that this church matched my own beliefs better than any other could. It was important to find the energy to get what I needed. Was it worth it? Definitely! For one hour every Sunday the experience is wonderful, and just talking about it now recharges my batteries!

Some tips: It was helpful to kind of humble myself and be willing to almost grovel! If necessary, be aware of the budget development cycle so that any access-related expenses can be planned for. Meanwhile, be aware that most clergy have their own discretionary funds!

An announcement about this workshop was published a few months ago in ALDAnews seeking input from people for whom access via sign language was not an option. How do people who depend on other communication go about obtaining access to their church? The replies we received are worth sharing.

ROBIN: One of the letters we received was from a woman who decided to try a church with a deaf congregation even though she herself does not sign. Although she had heard it might not be a positive experience, she went and later, said it was wonderful! She felt very welcome and explained that the minister's wife volunteered to sit next to her and write notes for her. So there was clearly warmness there. Another writer also told us of a similar, "very positive" experience at a deaf church.

JUDY: Another reader wrote and said she arranged with her minister to get a copy of his sermon notes before the service. My interpreter gets a copy of the complete sermon and the
hymns and any readings so she can prepare for the vocabulary. Now, some might say "Well, why don't you just give it all to the deaf person" but I really want everything that I would get if I could hear! We have announcements, we have a time when people in the congregation can get up and share concerns and good news and these impromptu moments are all important to me. I can't compromise on that point!

ROBIN: Last night we discovered we both have had the experience where the interpreter did not show up so we have had times where we didn't have that communication support. What happens at that point is going to depend on where you worship and the kind of service they have. At Judy's church it is more unstructured so she can't get much without the communication support. My church, Episcopal, is a strict church in that we have a book that tells us what to do all the time. So if there is no interpreter I miss the sermon and announcements but I still can bear with it. I don't want to do it often but I can tolerate it.

COMMENTS FROM THE FLOOR:
"I have a small laptop computer and I have several friends who are fairly good typists and I take my laptop and my typing friend along to meetings and she sits beside me and types out what is being said. We get on splendidly!

Robin made the point that when you as a deaf person go along to a hearing church, you get the feeling they regard you as somebody who needs help. I found that myself but a great many years ago, I started to think that's not the right attitude. What can I do to help these people? Well, I am a Methodist and we have a large number of lay preachers so I signed up for the lay preachers' course. You have to learn to overcome your fear of standing up and talking in a crowded church, and that's a big step! But I now find that not only do I make a positive contribution to the life of the church, but I tend to also have an even greater impact on its people. Someone hearing me might think "if faith has anything to do with overcoming a difficulty like his, what could it do for me?"
"I'm in the Christian Reformed church and the ministers in that church have never once asked me if I needed any help in understanding the services. Since I don't sign, an interpreter is not going to help me. My solution has been to have a very good friend who will take notes for me during the sermon so I can follow it. I don't expect her to do that for me forever! This workshop gives me some idea of how to approach the ministers at my church so I will be able to understand the service."

"I never had a good religious upbringing, all of my family were basically atheists. I am a deeply spiritual person, I feel it intuitively. I started practicing Tai Chi because I think it helps my health. I get access to it with persistence. I saw it, I needed it, and I kept after it until I found one very intelligent Chinese man, an expert at Tai Chi, who would make it accessible to me at his expense. He took me into his home and wrote everything. He would shout at me and show, show, show. I also met a Zen Buddhist master who did the same, but it took a lot of persistence on my part. Eventually it became a course of self-study in oriental religions and philosophy but along the way I did meet these people who were willing to take the extra step and make this accessible for me."

"I changed churches and became an Episcopalian because they have a prayer book and you can follow the service. I did have a big problem: They would read the first lesson, the second lesson, and the gospel. They would not print where the reading was in the Bible. I had to get that printed. I volunteered for this and worked every Friday at my church preparing the bulletin so it can be printed for me. My minister does not preach from text so I would almost fall asleep. It's very boring and I complained with no luck. However, guest speakers use a text and he makes sure it's printed for me. Some day I may get through to him. I keep trying and the squeaky wheel gets the grease. Some day he will get tired of me and give in!"

I think the woman here who goes to the Episcopal church and has trouble when there is something new in the service should go to the priest and say "Hey, I can't follow what's going
on if you put something new in. I want to know ahead of time." I think you need to make it plain to him — you have to speak up because otherwise it is just not fair to you.

Also, I was born into and active in a Presbyterian church, a very warm church. I taught church school and the minister always photocopied the sermon for me so I could understand it. I always sat right in the first or second row. He was very easy to lipread and he always looked at me, too. Then I joined the Christian Reformed church and now I feel like I'm going backwards because I don't get anything from the ministers at all. I'm having to really push hard. There's one other deaf person there who has a cochlear implant so she and I are trying very hard to get the church to meet our needs but it has been very difficult."

CONCLUSION: We have a common thread here in what we are all saying. We have to contact the clergy and tell them what we need. Most of the time they do not have a clue and they will never know what we need until we find the courage to tell them.
WOODY WAGA: First, let me say that we all have to know how we are perceived by an audience, and perception is the big P-word in society today. It lets us know how we're thought of by others and I just want to clear that up at the very inception. I think I know how I'm perceived by you. I'm a very funny guy and I'm also very dedicated to my work. But now we're speaking only of my work, and I take this very seriously. I am truly honored to be sharing this podium with my friend, Marylyn Howe, who probably most inspired and motivated me to get further involved in the work that I do in the deaf and hard of hearing community. The first word I learned in sign language was to communicate. To communicate means to get our thoughts across to other people. What I'm trying to get across to you this morning, along with Marylyn, is why it's important to know the kind of work CART reporters are doing around the country and truly around the world.

Steve introduced me as a Past President of the National Court Reporters Association. That is a group of 32,000 people, and I was obviously very active in that group. I was their president for a year. I harken back to somewhat of a joke, but it's a very serious one and it has to do with direction, focus, and where we are in life. I was responsible to 32,000 people and it made me think of the young boy and girl who were driving on their vacation in the State of Maine. They were lost and couldn't find their way. So they saw a farmer on the road and they stopped the farmer and they asked him, "Excuse me, do you know where the city of Augusta is?" The farmer scratched his head and said, "No, I don't think I know where Augusta is." They said, well, "Tell me, where is the city of Camden, Maine? It's a beautiful seaport city." The farmer scratched his head and said, "I don't know that either." And the boy said, "Well, tell me where is Portland, Maine, the southernmost city?" And the farmer scratched his head and said, "I don't know that either." The boy was rather upset and said, "You know, for a man living here for many years, you don't know very much about your state, do you?" And the farmer said, "No, I don't think I know that either, but I do know one thing: You're lost and I'm not."
Similarly, I felt that many people who were members of our organization, thousands upon thousands of people, had no direction. They were lost. They knew there was a city of Portland but they didn't know how to get there. What Marylyn and I are going to cover are some of the ingredients in the recipe of how to get services like CART. The various modalities that go into this kind of a service, and how it applies to the deaf and hard of hearing population, whether it is culturally deaf or late-deafened.

People immediately think about captioning and CART services as what you see on television by reading the captioning on the bottom of your screens. To be a CART reporter, you must be a realtime reporter. To be a captioner on television, you must be a realtime reporter. But to be a CART reporter, you don't have to be a captioner on television.

Now, that might sound a little confusing to you, but let me just explain a very strong distinction in our minds. I made a professional decision many years ago in my work, in my company, that I didn't want to work on television. I didn't want to work Saturday nights to cover the late news. I certainly did not want to do captioning at 2:00 o'clock in the morning to cover a sporting event from another country.

Most of the work of every CART reporter years ago was in the legal community, working as a court reporter. As a court reporter, we could either work in court or do what we call freelance. Freelance involved everything. Well, my decision was after doing this work -- I've been doing it for 35 years -- but after doing it for many, many years, I thought I am tired of working for lawyers.

I wanted to work with real people, to provide hands-on services for people who are really thankful and are not ungrateful for the services I do. Professionally speaking, court reporters were always very much taken advantage of, never thanked, and paid reluctantly. Well, I loved working with deaf people. I also knew that the deaf people that I knew, the friends — the Marylyn Howes and the Bill Grahams and all of the thousands of deaf people that I knew
in America and overseas — never wanted pity. They wanted cooperation. If you're real, it's very easy to put out cooperation. All of the people that I've gotten on teams like this are people that put out, whether you're getting paid one dollar or $100; it doesn't really matter. So I made this decision to work with people who might be deaf or hard of hearing who cannot really hear, rather than work with attorneys who refuse to listen but can hear. There's a great distinction in my mind about that.

In the next 75 minutes, Marylyn and I will be speaking about CART from a national perspective. The preparation that goes into being a CART reporter, the technology, the benefits, the funding necessary, your rights as a consumer of CART services, and how to create a network of CART services for yourself around the country. From my exposure to ALDA and other workshops that I have attended, each year I find that there are more and more people coming to your convention who really have never seen this before, who think that it's magic, that it just pops up on the screen. The only assistive device really necessary to get your communication database going is either reading hard copy or relying on these wonderful people, our signing interpreters.

Before I turn the stage over to Marylyn, let me say that there's a misconception in a lot of people's minds. The interpreters and CART reporters work together. Okay? We cover usually two different kinds of audiences and we are not in competition. We are professional colleagues and we work together. We cover two different groups, obviously. If you are late-deafened — hearing yesterday and late-deafened today — more than likely you cannot sign. But you can read. If you cannot read but only want to sign, for various personal reasons, or you can read and only want to sign, you will pay attention to a signing interpreter. That's fine. We will also be discussing later many, many other implications of where services like this can take you. Before I turn the floor over to Marylyn let me say also that Ed Varallo, an old friend and colleague of mine, is about the best CART Reporter in our business. We began long before there was any application of our services to the deaf community, and although he lives in Boston and I live in New Jersey, we communicate very,
very frequently on what additional services can be provided. In the course of the year when we don't see you, we do see some of you that live in my state and neighboring states, but we're contacted by people and there is always a new idea. It's like saying I'll tell you all of my good ideas today. Oh, no, why should I do that? I won't have any good ones tomorrow. Wrong! There's always a new idea tomorrow and we will find those new ideas because it's a changing environment. If we don't learn to live with change, we will be left behind. And we certainly don't want to be left behind. Having said that, I'll ask my friend and colleague, Marylyn Howe, to step up. I'll come right back.

MARYLYN HOWE: Thanks, Woody. I'm going to be talking today about my experiences as a consumer of CART services and as a co-developer of a CART program in Massachusetts. In Massachusetts, the users of CART services can call up our State Commission for the Deaf and Hard of Hearing and request a CART reporter, the very same way a person who uses sign language can call to ask for a sign language interpreter. It's a very, very similar type of program. How many people here have attended the first ALDAcon in 1989? Anybody? It was at Mercy Hospital in Chicago. Well, I'm going to explain to you what happened there in terms of our communication access. When we were planning that conference, Bill Graham and I were trying to figure out how could we best provide communication access for the population that we wanted to convene. We knew that the only common denominator was the printed word. We knew that some people used sign language. We knew that some people were really good at speechreading, but there was really no other common denominator besides reading the text or reading the printed word.

So we set up a display where the output went to the overhead projector and then onto a big screen. But we were using a typist, a very, very fast typist who typed at probably 100 words per minute. Now, any of you who have studied speech will know that 100 words per minute does not keep up with the rate of speech. One hundred words per minute is very, very slow in terms of speaking. So what happened was the typist, as good as she was, would listen, concentrate, and pick out those words that she thought were important for us to hear. Now,
that didn't really give us freedom of choice. It wasn't the most accessible form of communication, but it was a whole lot better than anything else we had available at the time.

I have to give credit to that setup, which we really very fondly called "ALDA crude," it was a rudimentary, very crude, form of captioning. At that first conference we also had access to one or two court reporters who were experimenting with computerizing their stenographic display, where the steno words would search the computer for a whole-word matchup in English, and then display it as English text. We actually saw some realtime writing, but it was in relatively small, much smaller type than what you are seeing here. It was very difficult to read in a huge room like this, a big group setup. Forty-two people attended that conference, all of us late-deafened. Also, one of the problems that we had with that particular type of setting was court reporters had software that showed us the homophones so that whenever anyone used a homophone, the software would say, for example, "I can {see/sea/C} that this is {to/two/too} hard {to/two/too} read. That's a very cumbersome way to read cold-running speech. It was up to us as the readers to pick out the homophone that we thought really best fit the picture. So you can see how far we've come today, with the technology changes that have happened.

Technology has been changing rapidly, and fortunately, the court reporting profession has been changing with it. The realtime reporters successfully convinced the manufacturers and the vendors of steno equipment that there was a growing need for better transliteration and for larger print. Eventually the software became available that we use today. It is called LapZOOM, so the text can become larger. The realtime writing skills that you see here today are absolutely extraordinary. Not just here in this room but throughout the conference because Woody has hand-picked the best and the brightest in the court reporting profession. They are typing or keying in on their steno machines at rates of about 225 to 300 words per minute. That's pretty fast. It means, for the most part, that they can keep up with the rate of speech, and they are typing almost verbatim, or as close to verbatim as they can get. You can pick out what you think is important to hear and not rely on somebody else's judgment.
Now, as a person who really loves technology, and because I was ecstatic at that very first ALDAcon that for the first time in twenty years I could really understand what people were saying, I went back to my home state of Massachusetts and I started squawking loudly at our Commission for the Deaf and Hard of Hearing that they were too focused on deaf culture. They were really not paying attention to the needs of the late-deafened population. So when the Deputy Commissioner heard me and then asked me, "Well, you tell us, how can we provide services to the late-deafened population?" I absolutely wasted no time in telling her about CART, computer-aided realtime translation. Fortunately, she was listening. So we rolled up our sleeves. She called people that she knew who were in the Massachusetts Shorthand Reporters Association. I went around and did a few presentations to that association, to let them know of our needs, and then finally the three groups convened. It was a match made in heaven: the Massachusetts Shorthand Reporters Association, the Massachusetts Commission for the Deaf and Hard of Hearing, and the ALDA-Boston chapter.

Those three groups got together over a period of probably a year. We sat down in many meetings and made decisions about how we could go about setting up a CART program in Massachusetts. And I'll be talking a little bit more about that later in this presentation. What I want to say, though, is that what you see here today is the state-of-the-art in realtime technology. But besides the technology, it is extremely important to remember that the CART reporters are to be cherished as much as the interpreters are to be cherished. They are to be revered by those of us who rely on the printed word to understand what others are saying. There are thousands and thousands of court reporters across North America, but only a relatively few of them are skilled in realtime writing. So that gives you a little bit of the background. Later I'll be talking to you about your rights under the Americans with Disabilities Act — your rights to access CART — and how to set up a program in your state. For now I'll turn it back to Woody, who will talk to you a little bit about the technology and some of the things that make it work such as the dictionary preparation and writing techniques. For example, if you have a complaint that a word doesn't show up on the screen, chances are really good that the particular word is not in the CART reporter's dictionary. So
it's really important before we give presentations that we share our materials with the CART reporter, so that he or she can make those changes and put the words in the dictionary and make the meeting or conference as accessible as possible.

SELECTING A CART REPORTER

WOODY WAGA: How to select a CART reporter, whether you are living in San Diego or Camden, New Jersey, is largely dependent on your exposure to the CART or court reporting scene in America. You're not really obligated to go out and attend conventions of court reporters or interpreters to find the very best in their field, but you should have a liaison. We are going to file with the board of directors of ALDA, a national list of all CART reporters available in every state and, those who have earned a new certification for CART reporters called Certified Realtime Reporter (CRR.)

That will give you a feeling of what is out there as far as our profession is concerned. Then, like calling your doctor or your carpenter, it is a matter of choice, and involves a level of familiarity, a comfort zone, so to speak, for working with those people. Sometimes you know as a consumer which technology better suits you. As coordinator of the realtime services for this convention, I had to make a decision weeks and weeks ago as to the technology needed for this building, for these rooms, the size of the room, the lighting; all of these things are very important. So I had to just draw the line and I said, let's try and use mostly TV monitors. Now, many of you like TV monitors because the clarity is pretty good versus an overhead device where sometimes the overhead is competing with the lights above your head which cause the contrast to be less sharp. It is a matter of individual taste. We know you can't please everyone.

I would like to discuss for a few moments the question of perfection and what that means. We all try in our fields of endeavor to be as perfect as we can in the application of our services. But this is an art. This is not a science that is so well developed that it can't be
challenged. Medicine is also an art. As we all know, there are mistakes in the medical profession. There is no real perfect system. As we have just seen, not even the jury system in America is perfect, but we try so hard to do our preparation to make sure that the database and vocabulary that is being used for each assignment comes as close to perfection as possible.

I have played a little game with my friend here, Ed, and I told him just before you sat down, and I told the interpreters too, there might be a few strange words I'm going to throw out just to show the audience what preparation is all about. We're not throwing out words necessarily that only apply to deaf people, because deaf people fit into the larger community worldwide. So suppose I were saying words like gasconade, and spondylolisthesis, hypochondriacal, or marsupial. These aren't words that we hear every day, but look! Look at the magic! It came up exactly as I was saying it. This is no real great trick. This was called preparation. The interpreters and CART reporter were prepared. All of the words that are esoteric and indigenous to your community and what might be spoken about at this meeting definitely are researched and inserted into our database.

But, you know, last night there was a sort of wild late-night party for about fifty or seventy five people that I had the misfortune — I mean fortune — to attend. Some friends from California were there last night and we were speaking about next year's ALDAcon and what might be necessary to provide CART for that convention. One of the thoughts was, maybe to get local people to do CART. I'm not criticizing my friends from California because it was a good question that requires a good answer. Maybe we can get some local people and just have them come in from San Francisco, not San Diego, and have them just do the work and you wouldn't have to bring these people with you.

Well, a party, when people are drinking and laughing, is really not the place to discuss true professionalism. But there are things that you should know that really make a difference. For example, suppose a very ambitious, intelligent, wonderful, giving person who's a new
person on the scene in the CART world or the interpreting world, a neophyte, gets exposed to a convention of 200 people. Their first exposure to the deaf world, deaf/hard of hearing, culturally deaf, late-deafened, what-have-you, that person doesn't realize it but his or her first time could be traumatizing. They feel left out. Very often that happens. That is a social/professional bridging problem that these people have to face. Additionally, they have to work pretty close to being perfect at the same time. They don't even know anything about deaf culture. They know one thing. They are court reporters. Well, it takes a very long time to become close to perfect in any field. So we don't work with new people. We don't work with people who have no exposure to your community. I think once again about the word communication — I think by really good and sincere communication we can learn that we really all live in one community and not separately. By the way, the 32,000 people who couldn't find their way in the state of Maine maybe will be able to find some direction.

There are other applications for the services -- and I'm jumping around, I realize, but I think it is important to feel comfortable with each other and I feel very comfortable telling you this. There are other applications that people like Ed and I and many others do. And I'll give you a few. One is "student captioning." I'm not challenging the educational placement issue of whether deaf children should be mainstreamed into traditional schooling or kept in a proprietary school for deaf students. I'm not challenging whether deafness is a culture or a disability. I'm not here to talk about that. But I am here to say that I know for a fact that there are certain deaf children who can be mainstreamed into a traditional school setting. I also know for a fact that there are certain students who, if kept behind when they turn twelve, thirteen, fourteen years old, are handicapped socially and sportswise. They don't progress the same way as other people do. They definitely don't read the same way. That's unfortunate because those same people, if given an opportunity, could be exposed to a more globalized form of education. We are trying very hard to work with some of these people.

We cannot carry them into a school, but once they're in that school we can try to make life easier for them. That's what we call "student captioning," or "classroom captioning."
actually have one person, if there's one deaf person in that classroom, sitting with the deaf student. Rather than putting the entire display up on a television screen or monitor, we would give them a computer screen or a notebook computer right in front of them. Which is not uncommon in the school setting today. Students do bring notebook computers to school. So they could be looking at that. Additionally, at the end of the class they can actually spit out a computer disk and give it to the student and have the entire course curriculum on that disk. They can go home and read it over and over again. Isn't it interesting? It's creating a new level of jealousy. The hearing students say, wait, that person is getting a disk and I have to sit there and write notes all day? But that same deaf student also has to pay attention to lipreading, notetaking, concentration. That's one application.

The three major sectors of the community affecting the kind of work that CART reporters do are government-related, association-related, and education-related. If you take all of those sectors, we have covered almost everything except for one other area, and that is the media. The media has enough exposure and enough money to take care of itself. They get covered. Of course, with the passage of the ADA, the media knows what its obligations are. There are still other areas. We're doing a wedding for a deaf woman in New York City. We're doing a bar mitzvah for a deaf boy who goes to a proprietary school in Massachusetts whose family lives in New Jersey and is coming back for his bar mitzvah and wants 35 of his deaf friends to attend the bar mitzvah. So they're sending a bus from Massachusetts to bring them to New Jersey. We're going to do all of his prayers in English and all of his readings from the Bible in English to appear in realtime, so his friends, both Jewish and not Jewish, can be reading it verbatim and be totally included in a religious setting. This is not something that's done very frequently. Of course, the church has had realtime volunteers for quite some time and (I'm Jewish so I can say this) synagogues have not had that at all. Obviously, a lot of the reading in a synagogue is in the Hebrew language, so that would not be possible. I go back to my statement as to why I would rather work with real people than lawyers.
Another reason, a perfect example, occurred in New Jersey. There is a profoundly deaf Russian man who was an engineer in Russia. He's over 50 years old. His language skills are terrible. He has a profound hearing loss. But he's an engineer and he wants to get a degree in America so he can continue his work as an engineer. He enrolled in the New Jersey Institute of Technology, a very well-respected engineering school. His problem is, he couldn't hear the teacher! If he could hear the teacher, he can't speak the language. How can he really sit there and learn? He failed every course his first semester. He failed every course the second semester. I contacted the school and we demonstrated the kind of work that we do and suggested maybe it would help him learn the language, and study the course for which he paid.

His reading comprehension in one year, went from eight percent to 80 percent. He is now speaking English pretty fluently. We communicate on the TTY every two days. His language, is so good it is obscenely intimidating. He is going somewhere. And we feel so good that he is accomplishing something as a visitor to our country, that he has now mastered the language and is now mastering his chosen art. He will probably become a licensed engineer in New Jersey in the next couple of years. That excites me. And it excites him, too. He reads the ADA. He knows everything. It's perfectly okay. He is now excited about being a professional American. He was given a computer like you see here.

Some applications require massive display of text, such as music. I love jazz. I don't like rock. But we were called about a year ago to do the Grateful Dead concert in Madison Square Garden. Since I don't know one Grateful Dead song, my first question was, "Why do you want this captioned?" And they said, "Well, there are about 50 or 75 late-deafened adults in the New York region who are "Deadheads" and want to go to the concert because they remember all of the music. I've been going to late-deafened adults karaoke parties for years and I know the kind of music they remember, so that's very understandable. Since I don't know very much about Grateful Dead music, I asked for the score of all of the music so I can build my database in my computer? And the Grateful Dead very politely said, "Drop
dead, because we don't give out our score to anyone." So I said, "Well, let me play one song and see what it sounds like" and I frankly, as a hearing person, could not understand too many of their words. There was very heavy music in the background. So they then objected to me even being in Madison Square Garden in front of many thousands of people. They said — this is really lack of knowledge — I would be too obtrusive, I would get in the way of their performance. The truth was that we would really be sitting in the pit, low down where nobody would see us and all of the people who were relying on the CART services would just see a screen. They said, "We want the better service. We want signing interpreters." I said, "Great! They're wonderful! And they like the Grateful Dead music. I think you should use them!" But they didn't know one thing. That when you're in a concert setting in a large theater like the Madison Square Garden, the lights are down and you really can't see the signing interpreter, so the interpreter would need a spotlight on him or her which would really take the attention away from the concert. But it was really fine with me because I didn't want to go anyway.

So we have a TV monitor, we have an overhead device, and we have a computer screen. As we said before, we live with change. There's always some new technology coming out. You will see a scrolling device as you would see in some of the opera houses in America, the translation from foreign language, from Italian or French or German into English. Instead of sitting there and reading in the dark, very often you will see a scrolling device. I know the Metropolitan Opera House in New York has that. We're now trying to bring that -- this room has about fifty or sixty people -- in a room this size so everyone can look and see it going across. It would resemble a newsreel like on Times Square going around the building and reading the news as it goes around. And that's very good. The Lexington School in New York uses that in their auditorium. And if you think of other applications, please, find me and we will try to influence technology people in our field to work on the manufacture of that application.
Let me discuss one other thing before Marylyn kicks me. That is ethics. We're very serious about the work that we do. Lawyers have ethics, doctors have ethics, you have ethics in your field, and we have ethics. One thing is very important about ethics. Let's take a session like the ALDAcon. There are self-help breakout sessions that Laurieann Chutis asks you to attend. Some of them involve alcoholism or drug use. Some involve situations in your home life. Some involve group psychology sessions where you discuss some very personal things involving everything that affects your behavior patterns. What we hear, what we write stays in that room. It doesn't leave. We don't get paid for gossip. And a professional person doesn't thrive on gossip. Do we have feelings? Yes! Have I cried doing my work in my lifetime? Many times. That's because we're human. But what we hear stays in that room.

I have worked in drug rehabilitation, alcoholism, and for a deaf psychologist who interviews her patients in New Jersey. What we hear stays in that room. Very often what I elect to not use names when writing. Because I know that very often in anonymous groups names are not necessary, just the input. First and foremost, confidentiality is respected. We never violate a conflict of interest or the possibility of the perception of a conflict of interest. Suppose two people who were deaf in New Jersey have asked me to render my CART services in a business setting and one of them was my friend. I would make that known to the other party, to be sure that they didn't leave that room feeling that I was going to do more for one than for the other. This lady here is a professional friend of mine, Nancy Kingsley, from New Jersey. We attend meetings together. When the meeting is over, unless it is a public meeting, we don't talk about it. And I would never do anything special for her. Professionally I might, but not on a personal level as a result of that meeting. The services we offer to one we offer to all. That's very important.

So I ask you to consider that when using a CART person in the future. Please don't ask them to bend any of these professional and ethical rules that we employ for ourselves. A general comment is we try to never go out of role. Ed, I am sure, is listening to me speaking and he has some very personal thoughts of his own on these issues. We all do. If he were to stand
up now and start speaking and correcting what I just said about ethics or maybe add something to it, that would be called "going out of role." We generally don't do that. I must admit that I have violated that from time to time because I just couldn't resist! But it's really not supposed to happen. This is also true for the interpreting world. You don't go out of role. Very often miscommunication happens among deaf people. I could clear it up. But it's not my responsibility, nor is it within my province to do that. It is outright insulting at times when Nancy says to Joe, "Joe, would you like lunch with me today?" And Joe says "What about the bunch?" And Nancy said "No, I said would you like lunch with me today." And Joe said "I don't have a bunch." And they go back and forth. Well, it would be very easy for me to stop them and say "Nancy, he didn't understand. He thought you meant, "a bunch," like a bunch of bananas, but he really didn't understand the word lunch. "Now, that took about two minutes to explain. I could have cleared that up in about five seconds on the screen. But it is not the CART reporter's place to do that. I ask you to please respect that. Marylyn, would you like to wind up before we have some questions?

MARYLYN HOWE: Okay, sure. I just want to talk about our rights under the ADA. You have a right to communication access. You have a right to advocate for yourself and others who need CART. The packets that I have prepared for you provide just a little bit of resource information to help you as you go home and think about how you can set up a program on your own. In the packet I have included a document from the Federal Register called the Final Rule. Anybody that understands federal papers knows there's usually a proposed rule, a time for people to comment on that proposed rule, and then a Final Rule which for the ADA is issued by the Department of Justice. There is a section in here that is particularly important for us called "Auxiliary Aids and Services." I quote just a tiny bit of it, it says: "The Department of Justice has added video text displays, computer-aided transcription services, and open and closed captioning to the list of examples for auxiliary aids and services. Transcription services (meaning CART) are used to relay orally delivered material almost simultaneously in written form to persons who are deaf or hard of hearing." This refers to CART technology that is often used at conferences, conventions, public
hearings, et cetera. Your right to communication access (i.e. CART), is in the ADA. I have used that particular piece of legislation a lot in my business, in my profession. I travel all over the world sometimes, mostly in this country, sometimes in Canada. Every conference that I go to I always have a CART reporter at my side. So I probably am really spoiled! But it's because I have self-advocated and I have insisted to the conference planners that I absolutely need CART services.

Woody has assisted me sometimes. I went to Vancouver last summer and I had a CART reporter from Seattle, Washington drive up to assist me. The conference coordinators had to pay for all of his services because it is my right to communication access. It is really important for you to understand that when you get a conference brochure or a registration form, you will see some options on the registration form. "Please check off if you need a sign language interpreter. Please check off if you need large-print text formats," whatever, all those accessible formats that are available. If I don't see CART down there, I check it off and write it in myself. I add, "Please call me if you have questions as to what CART service is."

Nine times out of ten they don't call because they think that this is some weirdo just looking for attention. So I make it a point to call them back, a good few weeks prior to the conference, to ask if they reviewed my registration forms? Do you understand my need for CART? More often than not, they need a full explanation of what the service is. I'm usually happy to find a CART reporter in that particular area if they don't know who to go to or who to approach because I have a pretty good network of contacts. Thanks to Woody, Ed, and others, I have learned to advocate for myself. I think that's extremely important for all of us to be doing. Because once we all do that, we will have more communication access through CART. It really, really aggravated me very recently when I got a conference brochure from Gallaudet University, and on that brochure it said all of the workshops and all of the seminars will be sign language interpreted but only the plenary sessions will be available in CART. So what they did, in effect, was to say to me, "You can only come to the plenary sessions if you
want to go, but forget all the workshops and the seminars. They're not going to be available
to you." I said, "Uh-uh, that's not acceptable to me and you're violating the ADA by telling
me that I can only have CART at the plenary sessions and that's it.

So that's where the law comes in. That's where it's important for you to really self-advocate
and to speak up for your rights to enjoy CART service. Okay, I just want to talk about what
happened in Massachusetts. We had two major goals when we were setting up the program
in Massachusetts. The goal actually was to develop a statewide system of (1) trained and
certified CART reporters and, very importantly, (2) informed purchasing agencies (so that
persons who are deaf and hard of hearing would have access to CART reporting as one type
of interpreting service whenever they need it). So, in other words, it wasn't enough for us to
just consider that we're going to set up the program. We had to set up the demand and we
had to set up the supply. We sat down — Ed was one of our co-developers of this program
— and we had to think through all of the stages and all of the steps and what we were going
to be doing. We came up with a list of components of the CART reporter system and these
were just for our development purposes and our objectives. One, we needed standards for
certification and training competence. Two, we needed certification procedures. Three,
training curricula was needed for training on-site. We invited court reporters to come in who
were really interested in doing CART reporting and trained them on-site at their own pace.
We would stand up and give presentations; they would come in with their own steno
machines and computers, and they would key in and self-test themselves to see whether or
not they had the skill or whether or not they wanted to continue to be trained to learn the
skills.

We set up written guidelines for CART reporters on the state contract. We developed a
manual which is a draft, actually, of what we call professional ethics and standards. Now, the
National Court Reporters Association already has a very substantive document on professional
standards and ethics. But I believe it only addresses ethics in the courtroom and in the
classroom settings. There's nothing about being in a nontraditional setting like the self-help
meetings that Woody just spoke to you about a moment ago. We needed to figure out some "how-to" guidelines for CART reporters. We needed to incorporate CART reporting into state agency purchase of service blanket types of interpreting. In other words, we had to let the various state agencies know that they were responsible for providing CART to a consumer who needed it and they were also responsible for paying for it. We needed to look at what kinds of information we needed to develop for potential consumers of the service. You know that this brings us back again to self-advocacy. For example, a major corporation like AT&T was coming to our area to do some big, big display during Deaf Awareness Week and they would invite all of the deaf consumers in the state and say we will provide interpreters for you. Yet, many of my colleagues would say to me, "Oh, shoot, I can't go because they're not offering CART." To me that's not acceptable. To me, I have to say to them, it's your (the consumer) responsibility. If you want to go, call and make sure that they have CART. You tell them that you need it. So that's what all of you have to be thinking about in terms of acquiring these services and setting up your own network.

In this particular folder I put together, it has the MCDHH — Massachusetts Commission for the Deaf and Hard of Hearing — fact sheet on computer-aided realtime translation: What is it, who uses it, how to acquire it, when can I use a CART reporter, who pays for it, where do I request a CART reporter, and how to get more information. This goes out all over the state, so we really are trying to get that network going. We have done a pretty good job of it, I think, because statistically in fiscal year '91 when the program began we had 86 requests for CART; in fiscal year '92 it went up to 126, and in fiscal year '95 it's 660. So that's quite a jump. We have the statistics on how many of those requests we were able to fulfill. Because there's not always a CART reporter available when I need to go to a particular staff meeting or whatever, so they are not always able to fill it. What did we do with funding? Before I worked in my present job I had a job in private industry at Little, Brown & Company, Publishers in Boston. When I needed a CART reporter for a staff meeting, that agency had a list of CART reporters that they could call and it was a free market. The CART reporter could charge what was the going rate and what the agency could bear. So there was an
agreement between the two of them and I was completely out of any negotiations. Now, when a state agency or some other business wants to go through the Commission for the Deaf and Hard of Hearing referral network, then the CART reporter is bound by the state contract rates, the same way that the interpreter services work. There are state contract rates that stipulate "I'll accept this job, my minimum is for three hours, with one hour of preparation time." They get paid for the preparation time that they put into it. But even if my meeting only goes for one hour, they still will get paid for the three hours that they put into it, because that's the minimum that they will get paid.

If they are going to go over an hour, they must get a break for five minutes after every hour. There are other criteria that are built into the contract. They can get paid, I believe, now for travel expenses and parking, whatever the IRS allows, whether it's 30 cents per mile or something like that.

So all of those things are built into the state contract. But before the CART reporter can sign that state contract he or she must go through our training program and then go through a mentoring program. So, for example, if Ed comes to my office and does a job for me while I'm at work, he may bring someone with him who is a trainee and who sits there and does the very same thing. But I don't pay attention to the trainee. He or she is just doing like a self-test, to see whether or not he or she is ready to sign a contract. We have developed a statewide draft of guidelines and operational standards that we are trying to finalize and make very professional.

So if you are interested in getting a CART reporter network started in your state, you must contact whatever state agency you know of that serves the deaf and hard of hearing community, let them know it's available, let them know that other states or at least Massachusetts has done this -- and I'm happy to share any information that any of you want. It behooves the states to get on the ball and to set up the network. I also have included in this packet the TDD numbers of every assistive technology project in the country. An
assistive technology project typically does not fund or provide direct services. But it is an agency that can help you start to develop your network, start to find where the realtime reporters are in your state and work with you to get a program like this going.

QUESTIONS

There is a new agency in Naples, Florida that wrote to me. They request that if people want their service, they have to have their own personal laptop. I had never heard that. Is it true?

No. In order to see CART, you obviously do not need a laptop in front of you. If you are receiving student captioning in a classroom setting, the CART reporter would bring his or her own computer for you to read. You can use your own computer notebook. You don't need your own to read, but you could use your own, or one provided to you by the CART reporter. However, in other settings you can cable other computers to the host computer and have other people reading from computers. It is really based on the logistics of the room. A room this size, you would not want to sit here with an individual computer unless you had a visual problem and you had to look really closely at a screen. And that's a possibility for some of you, but usually you don't have to bring your own computer. I prefer that you don't.

I have a question about one-line captioning. The New York League for the Hard of Hearing gave a fund-raiser at a nightclub and they had this one line. But it was impossible to get the joke. If one word was a little off, you couldn't reread.

Yes, if one word is mistranslated, you won't get the joke. If it's also a visual problem by looking at one line going across, make that known to the New York League of the Hard of Hearing or SHHH of New York and whoever they're using. I happen to know the person in New York they use and he does use one line. Some people find it very easy to read. One line requires more technology and it is not cheaper.
What about voice recognition. Will that eventually eliminate you and what stage is it at? Will I eventually be able to carry around a little computer and it'll do the voice recognition?

Voice recognition is not in its infancy, but I really have no fear that it's going to replace me. Well, I definitely think there's a use for voice recognition, but not in the verbatim setting that we are used to reporting as court reporters and CART reporters. Our language, the English language, has too many interconnecting prefixes and suffixes in our vocabulary. If said faster than say 100 words per minute, they will bring the words together. If going about 250 words a minute, those words would be coming together and creating different words. I'll give you one easy word combination. Discovery...research. It might come out as, quote, discover research. You can only look at all of the words in our language, look at the last pronounced syllable and the next pronounced syllable of the next word and you will see that you can actually be causing yourself a great embarrassment. So we have no real fear of being replaced by it. But I think it is a very good service for clerical work. Voice recognition is very good for computer commands. I can actually talk to my computer and say the word "cap" and have the next word capitalized. I can say "DS" and a dollar sign would appear. But that has nothing to do with English translation.

What would be the price to have your services at a private party or any kind of affair, for private people?

The price varies because each situation really varies depending on the technology needed, the setting, and the travel requirements. New York City is a particular problem. I'm from New York. You have to bring everything in the building at one time. New York has a particular problem like many large cities. It's called theft. I have to bring everything in the building at the same time. Can you imagine carrying this at one time, my computer, my computerized Stenotype machine, my cabling, and my equipment to get the text onto a screen? You have to use carts to bring it in. The second you leave it unattended, it's stolen. We have had
thefts in hotels at ALDAcon meetings around the country and once it's stolen, it's stolen. My whole life is in that computer. Ed has hundreds of thousands of entries in that computer that cannot be duplicated. So it's very important to us.

**Would you come to Freeport, Bahamas? I'm having a party there.**

The answer is, with enough notice, we can provide coverage anywhere. We've done this around the world. Marylyn had a request to go to Vancouver. Price was a consideration, but with enough notice we can provide that coverage anywhere.

I live in New York, too, and I have used interpreters before but I would enjoy movies and theater if I could read the script. I would enjoy it perfectly if there was some captioning. My question to you is, is there any captioning technology that is now available that we can apply here to a situation like this?

Does anyone know of a company called Clozed, I think it is? It is a product that needed funding to get captioning in the movie theaters of America. So what is reasonable access and accommodation? Why should a deaf person, when he wants to watch a movie called "The Godfather," have to go to Blockbuster and rent it and bring it home and watch it. Part of enjoying a movie is going out of the house, also. Part of it is getting out and having dinner in a restaurant and sitting in a theater. So why should a deaf person be obligated to go home and watch a movie in the confines of their room? That's called not fair. If you believe in the ADA, you believe in doing what's fair and not just providing lip service — actually putting out. There should be a crying plea out there to get reasonable accommodation into the theaters. This gentleman has a very, very --in my opinion -- legitimate request. Why can't you go into a theater? Well, the technology is there. There is a show on Broadway called "Tommy." It's about a deaf boy and I begged the producer, let us go in and put captioning in versus just a loop system that they have in the theater. And they said, "No, we don't need it, the loop is enough, we've been using it for years." And I said, "For a show like this, don't
you want to display the very latest in technology?" And the producer had a one-word answer, the answer was "No."

I just wanted to say there is a thing that is being piloted called Rear Window. It is being piloted at the Science and Space Museum at the Smithsonian. And it is supposed to be quite good. However, it requires a lot of technical changes in how things are done. But it allows the person to have at each seat, to get something that they could have literally like a teleprompter. It's supposed to be very nice from what I've heard from people who have seen it.

WOODY WAGA: That is called Rear Window where each person has an individual screen. Tomorrow's luncheon will be outside and we are trying to set these TV monitors up all over the tent for people to see while also looking at signing interpreters. So technology is advancing. If it can be done individually, fine. Remember, there's always a glitch and we are trying very hard to work them out.

MARYLYN HOWE: I would just like to add that I have been on a pilot committee at WGBH, which houses the National Center for Accessible Media. We have gone to workshops where we have sat down and looked at all different types of prototypes that might be available for captioning in the movie theaters and there's about three or four different types. So in December we will be going to New York to look at some of the most advanced technology on captioning in the nontraditional settings, like a movie theater for example. All of this is still in the development stage. But it should happen in the future.

WOODY WAGA: Well, we were very ambitious with this group and we had a lot to say. I have one more thing to say. I have a lot more to say but one more thing I am going to take the time and discuss with the deaf group. And that is medical care. I work with doctors who have deaf patients all over America and we have the technology now to do remote captioning. If we wanted, all of this text that Ed is putting up on this TV monitor could be seen in Tokyo
or New York City or Atlanta, Georgia, or anywhere via telecommunications. If we can do it from this conference setting, why can't we do it in doctors' offices and hospitals also?

Because deaf people are misdiagnosed. Do you have any allergies? The person just got shot in the chest by a gun and the doctor is saying, "Do you have any allergies" and the doctor can't sign and the person is in shock. The person says, "No, just fix me." So the doctor obviously gives him some medication and he reacts adversely to the medication and dies. So we think that there's an application -- I know there's an application -- for both CART and signing interpreters in hospitals on a 24-hour call basis. It can even be done remotely. All you need is a telephone and a microphone and it can be done remotely and then the doctor can read what the person has to say or, more importantly, the person can read what the doctor has to say. We're working on that right now. In the City of New York there's only one hospital that has 24-hour call for interpretation -- not CART interpretation, but sign language interpreters; that's at Beth Israel Hospital downtown. Previously, they tried it in Bellevue Hospital in midtown Manhattan and they didn't get great cooperation. So, let's learn to work with what's going on out there.

Marylyn is handing out more folders. There is also an article I wrote some years ago on ALDA conventions and what we go through here and I just got a copy faxed into the hotel. It will be on the distribution table also. Thank you very much for attending. I enjoyed being with you and so did Marylyn.
This workshop used a talk show format to draw heavily on audience participation, sharing experiences and getting advice and ideas for resolving problems. The impetus for our discussion was using an idea from David Letterman in creating a Top 10 List of common problems we'd heard from the late-deafened and hearing couples or partners we'd polled. Fourteen common problems were discussed. Comments from the audience regarding each problem are listed.

1. **Dealing with the energy required to communicate effectively.**

"At night we'll be lying in bed and the lights are out, his hearing aid is out, and he starts talking to me. I get frustrated."

"It's hard sometimes just to talk. He has a moustache and it's hard to lipread."

"Trying to get across what we are trying to say to each other takes a lot of energy and effort."

"Because I think communication is the most important thing in any relationship, it's probably the thing that my wife and I spend the most energy on. But communication is a two-way street, so we both have to give fifty-fifty."

"Whatever rules that we try to set up, if there is one rule that the deaf person or the hearing person wants, then both of us have to do it. It's not okay for me to be able to speak or holler from another room and expect him to understand or come in if he's not able to do it too."
2. Unrealistic expectations that a cochlear implant, hearing aid, sign language, lipreading, or other communication accommodations will solve all problems, and having to learn to take advantage of them together.

"I know signs pretty good now, but my wife is really good and she thinks my signs should be better. But I still miss a lot."

"We realize that hearing aids are not magic; they don't solve all your problems."

3. Fear of a diminished social life as a couple -- loss of friends, difficulty enjoying things such as movies, theater, parties, family events.

"My boyfriend and I don't go to movies because I don't enjoy them anymore. We watch videos at home."

"It's hard for us to find things. It's not that I don't like to do them, but that I don't like to do them anymore because I can't hear when he's talking to 20 people at once."

"We find a happy medium, If we go to a deaf event, I'll reverse for her. When we go to a hearing event, she signs for me."

"Sometimes my ex-wife would say something to me and I would not hear it clearly and would ask her to repeat. After a while she thought I was just not paying attention to her and that started a lot of arguments between us. I didn't know I was losing my hearing. I was in denial."

"I think partners should look at maybe trading in houses. I'm finding out more and more instead of having a full wall, have a half of a wall or maintain a rounded corner instead of a straight corner because sound is able to go through that. So maybe we could look
into trading in objects such as houses and redesigning things instead of trading all our partners."

"Part of the problem I have had with relationships is that lots of times your wife will want to mother you and she will want to do too much for you and you have to stop that and say 'wait a minute, I want to do this myself.'"

4. The hearing partner being overprotective or trying to be an entry gate to the world.

"If you married a hearing person who minimizes your problems and difficulties in the hearing world, it causes communication problems. [My husband] was gone all the time and the other part was that he didn't think I was having any problems because I was competent. He thought I was making too much out of being disabled. He wasn't making enough out of it."

"I think assertiveness is important, and that's hard, especially for women. Eventually you start to become more comfortable."

"Another key is education. If both people are willing to communicate and you're willing to say 'Stop, this isn't what I need, you're overstepping your boundaries', it works."

"He's got things that I'm ignorant about too, and if you can remember not to get upset when they are being ignorant, [it helps to] just stop and explain."

"You have to be willing to go over and over it sometimes. Old habits die hard. But I also think that if you explain what's going on with your feelings and stuff, they listen better."
5. **Assuming the hearing partner can communicate -- from another room, over the noise of the hair dryer, etc.**

"Since I can hear, and the design of our house is somewhat open but not visually open, I can hear my wife from almost any room in the house. But it is impossible, of course, the other way around. So I listen a lot, but when a response is required, it sometimes means either waiting, in which case she may get impatient and feel, "I'm not listening", or I have to leave what I'm doing and get up and go to the room she's in or wait for her to hunt me down."

"I knew a hearing woman who was deathly ill lying in bed. She could hear the spaghetti boiling over on the stove. Her husband who is deaf had a beeper, so she called relay and said 'turn down the spaghetti on the stove'. So one thing deaf people can do is wear beepers and call through the relay."

"My wife can hear and I can't. When I call her from another room she can respond but she says 'It's not fair for me, for you to expect me to drop everything and run.' So I have to seek her out in the house. She taught me to respect her hearing and not take advantage of it."

"I want to speak for my hearing wife's viewpoint. I like to be social and go to parties where they have signing and captioning, and I'm like the person who said 'I don't want to go to those hearing parties because I can't participate and I'm left out'. My wife's viewpoint is 'I go to your type of boring parties and I'm not a very good signer and I feel I'm missing a lot, so if I go to your parties we should compromise sometimes. And I tried it once. I brought a book. She thought I was rude. But it was the only way I could pass the time, I was so bored. I just took out my book and started reading. So that didn't work either. She has a viewpoint that we should take turns and I say 'No, no,
you can do both -- you can do some signing and enjoy this one, and you can enjoy the other and I can only enjoy one'. So I'm not willing to compromise in this situation."

"At ALDA in New Jersey, we have parties with hearing spouses. They are welcome and expected. Maybe a third to half the people are hearing, and talk to each other. But most of them know how to communicate with deaf people. And everybody has a good time so you can be happy if you bring them both together."

"I think it is important to remember that it's okay even though you're married to have separate lives and goals. Instead of fighting when you're at a party, go off to your separate parties and then come back together and share."

"I feel that the point of marriage is to be together, to share things. My husband used to be hearing and he has passed away. But it was never a problem during our marriage. I mean, I could read lips real well, and when we were at events, when we had children, he would mouth the words for me. We had a really good marriage, so I think love becomes the most important issue and being together and sharing things."

6. **Fear of a threat to the partner's career due to the perception that the hearing loss diminishes capability and fear of the loss of identify.**

"About fifteen years ago, he was working for a company where he had to associate with a lot of physicians, and I was expected to be the good party wife. That means I was expected to go and perform in social situations and make him look good. Doing that when your deaf is not an easy thing to do."
7. **Feedback from the partner being taken as criticism.**

"My wife and I went to separate counselors and I found that my frustration was that I was blaming her and it really had nothing to do with our relationship."

"If I was in a social situation and experiencing problems, I had to ask him what was going on. He would get annoyed, and then I would feel guilty that I was bothering him."

"Sometimes you're trying to tell the other person that you don't like something, and then you're trying to explain that you want things to be better or different because it hurts your feelings. Then they take that as being critical of them as a person and not their behavior."

"One thing is that I don't hear how to say something and a lot of times I stop myself because I don't know how to pronounce the word. And then if you smile, they know that I'm teasing, but I can't smile. Sometimes I have to stop myself and ask what someone means and that helps us a lot."

"I had to drive 133 miles to go to a deaf counselor. It was not easy on my time, but my wife and I both agreed that if we were going to benefit we needed someone who could communicate with me. We didn't want a third person there, an interpreter. And the counselor was a woman so that was an acceptable compromise for my wife."

8. **A partner misunderstands what was said and bluffs that they understood.**

"I suppose I'm not comfortable being deaf. It almost feels like sometimes I'm a burden and I want to make it go away."
"A lot of times my husband is extremely impatient with me when I cannot understand. If I ask him to repeat over and over, he gets madder and madder and madder. Rather than starting a fight or argument, I will pretend like I heard what he said. It may not be right, but that's what I do."

"I don't know if I am bluffing. So many words sound the same and some words will fit the sentence even if it is the wrong word. But it will fit the sentence anyway, so a lot of times, unless I have the sentence repeated or see it in writing, I will misinterpret what he said. But I wasn't bluffing, I thought that's what he said."

"Not just with my partner but a lot of times, especially when I'm working with people who aren't familiar with being with hearing impaired and deaf people. I explain to all my teachers that if I answer inappropriately, that's usually a good sign I didn't understand. Sometimes it works."

"I have learned to admit that I don't lipread perfectly. I'm a very good lip reader but I like to say to people, 'Let me tell you what I think you said, and then tell me if I'm right'. And the things people say are what I thought I saw. And it's really fun and it really breaks the ice and the stress of struggling with lipreading. And making people laugh is a real benefit."

"Some of us bluff because we get tired of hearing people, when asked to repeat a second time, saying to us 'Oh, never mind."

9. **Partner feels rejected because communication has become difficult.**

"In the beginning, my wife and I solved the problem in just having her answer the phone all the time. Sometimes I can understand some people, if I know what we're talking about. But if somebody is calling and I don't know who is calling, I have too much
difficulty. So she suddenly earned the responsibility of always being the one to answer the phone. And this was fine in the beginning. But after a while she got tired of it. You know, we are sitting down to eat and the phone rings. Or she's outside and I'm in the house and the phone is ringing. She has to stop everything and come in. What we did was we ended up getting a pager. When the phone rings, the message is on the phone, it says to call the pager. Once I have the number, then I can take the time to call the person back and take on some responsibility. I can call back through the relay service and I'm on top of it."

"My husband gives out the relay number for us. And I don't take messages for him. They call back, and it's fine."

"I depend pretty much totally on my husband communicating for me," he makes all the phone calls, which really aggravates him, because he also works full-time and has very little time to do it. So in his free time, he's spending all day making his phone calls and my phone calls and our phone calls. When we are out in public, I can always hear him, but I usually can't hear or understand other people. So he always has to tell me what other people are saying. And that bothers him. After coming here I'm learning that I can be a little more independent, but I have been losing my hearing for about five years, and I'm just not used to it yet."  

"I think this was one issue that sent my wife and I to counseling. Because she sort of wanted me to be her interpreter and my sign language was not good enough. I also was too much of a participant to be an interpreter because of my own personality. I'm not sure that there was a specific solution reached, but an understanding, a realization that maybe she was putting too much expectation on me."
10. **Blaming the hearing loss for what is really a preexisting problem amplified by the hearing loss.**

"We have always had somewhat of a communication problem, basically in that he never listened to me. I'm concerned about what will happen when my hearing gets worse, and I'm afraid our communication is going to get even worse."

"The problem you have before the hearing loss of not being willing to listen to one another, it's only amplified after you have the hearing loss where you can no longer hear each other."

11. **Dealing with feelings of guilt because a partner misses something or because of feeling frustrated or angry about something that isn't the partner's fault.**

"We have a rule in my house. We have a calendar on the wall. If we have something to do, we write on the set day. If it isn't on the calendar, I don't know about it. When I plan something, I write it on the calendar. That way either partner can't say we are going to do something else if there is a conflict on the calendar. We made the rule because we ran into problems all the time."

"He's not allowed to shout in the house when we argue. I can't raise my voice because he can't do it, so if I can do it, then he can do it. We try and balance this out. Every time we run into problems, we sit down and we talk and we make another rule and that really helps us. And we have been married fifteen years."
12. A partner gives up after trying to repeat something three times.

"One solution is to use a different word. You know, if you can't just get one word that the person is saying, try and think of another word similar to it to replace it. If you still can't do it, get a piece of paper and write the damn thing down."

"One of the hardest things I find too is when you're talking about one subject and suddenly switch to another. You need a clue as to what they are talking about."

"It works both ways sometimes. The hard of hearing person changes the subject and the hearing person gets lost."

"We made an absolute rule, two times then write it down and that really calmed things down."


"A hard of hearing person says there's no problem; the hearing person says there is."

"Or vice-versa; it's hard to argue that."

CONCLUSION

At the close of the workshop, we emphasized that these problems were not the only problems but that they were ones we hear often in talking with people. We found during our discussions that often a problem applied to both the hearing and late-deafened partner. For example, where a partner talked about giving up after trying to repeat something an average of three times, we heard this from both deaf and hearing partners.
We also found that a lot of these problems can be resolved. All it takes is that two people really care about each other. A participant in the workshop said it best:

"I think one of the most important things is not to give up. Keep working on the problem. Just keep going on and on and working to recognize the problem and not put it off to the side. Stop, sit down and say 'Hey, what are we going to do about this?' Then you can make a rule. Then when this problem happens next time, we know what to do about it."
ALL CAPTIONS ARE NOT CREATED EQUAL: ADVOCATING FOR QUALITY CAPTIONS

Paul Berkay, Ph.D.

Although not mandated by law, most network broadcasters and home video producers provide closed captions for their television programs and home videotapes. There are industry standards specifying what constitutes quality captioning, but there are no laws that require that broadcasters and producers adhere to these standards. Federal law requires universities and public accommodations to provide captions, but meeting industry standards for caption quality are not part of this legislation.

Most broadcasters and producers are not aware of the quality of their captions, as they do not monitor or spot check the captions that accompany their programs. It is not unusual for a broadcaster to be unaware that the captions for a program are illegible or have cut out completely. Often home videos are shipped with a closed caption symbol on the box, but there is not a caption to be found on the videotape.

If captions are to be of high quality, they must be requested or demanded by consumers. In order to make an informed request for quality captions, the consumer should be able to obtain answers to two questions:

1. Which of the five available captioning systems is the broadcaster or video producer using to create the captions?
2. Is the broadcaster or video producer using the chosen captioning system to its best advantage?

The purpose of this paper is to prepare the consumer to answer these questions so that he or she can advocate for the best possible captions. First, a brief history of captions will be presented. This will be followed by a discussion of the different captioning systems and methods, with emphasis on when it is appropriate to use each system. Finally, a discussion
on advocating for quality captions will include information about what can be expected from each system and what the consumer can ask for.

**History of Captions**

In 1971, the National Bureau of Standards (NBS) developed the open-caption concept, and that same year, the Public Broadcasting System (PBS) in Boston began to show television programs with the captions opened (Carney & Verlinde, 1987). At that time, some hearing television audience members objected to the presence of open captions, claiming that they were distracting. In order to continue to provide captions for the deaf and hard-of-hearing television audience, a closed-captioning system was proposed by the networks, and in 1972, PBS began to develop the technology (Cronin, 1980). Line 21 of the vertical blanking interval of the television signal was set aside in 1976 by the Federal Communications Commission (FCC) for closed-captioned television. By 1980, PBS, the American Broadcasting System (ABC), and the National Broadcasting System (NBC) aired 20 hours per week of closed-captioned programming. The captions were opened by consumers through the use of decoder units manufactured and marketed by the National Captioning Institute (NCI). Some pre-recorded videotapes rented or sold in stores started to become closed captioned in 1981 (Carney & Verlinde), and a real-time captioning system was available by 1982 (Block & Okrand, 1983). Three major broadcasts that used realtime closed-captioning in 1982 were the Academy Awards, the launch of the space shuttle Columbia, and ABC's *World News Tonight*. The 1990's have found a great increase in the amount of captioned network programming, and as of July 1993, caption decoder units were replaced by decoder chips built into newly manufactured television sets, as mandated by Federal law (Gallaudet University, 1992; The Television Decoder Circuitry Act of 1990).
Captioning Systems and Methods

Captioned television programs are not produced with a sole captioning method or system. There are five systems to choose from and several factors that must be considered when captioning videotapes, such as (a) type of captioning system, (b) closed vs. open captions, (c) roll-up vs. pop-on captions, and (d) verbatim vs. edited captions. Each of these issues must be addressed before captions are produced.

Type of Captioning System

There are five types of captioning systems that employ quite different processes: (a) off-line captioning, (b) real-time captioning, (c) live display, (d) newsroom computer captions, and (e) character generated captions.

Off-line Captioning

Off-line (or pre-recorded) captions are generated after the production of a videotape (Gallaudet, 1992). With off-line captioning, the captions are carefully edited to eliminate typographical errors (National Captioning Institute, 1991; Salomon & Freda, 1992). An attempt is made to have the captions pop on as they are being spoken and to change the captions with the camera shots or speakers (Carney & Verlinde, 1987). When using off-line captioning, a time code displaying the minutes and seconds of each frame can be placed on a master videotape to assist with timing (Cronin, 1980; Salomon & Freda, 1992). In order to use an off-line system, captioning software, a computer, and an encoder are needed (Salomon & Freda, 1992). With off-line captioning, approximately 25 hours of staff time is required to caption one hour of programming (Salomon & Freda, 1992). The typical off-line captioning process was described by Salomon and Freda as follows:

1. While viewing a previously produced videotape, the captioner types the captions in a computer file using a captioning software. During this process, the captioner also uses the captioning software to designate timing and placement of the captions.
2. When all of the captions have been created (including the timing and placement decisions), an encoder is used to encode the captions on to the video signal of a copy of the videotape.

There is a variation of the above process. Some captioners do not create the captions while viewing the videotape. In some instances, a clerical worker uses a dictaphone and word processing software to develop a transcript from an audio tape of a previously produced program. While viewing the videotape, the captioner edits the previously prepared word processing file, instead of keying in the captions.

**Real-time captioning.** With real-time captioning, the captions are produced and generated live (Gallaudet, 1992). A court stenographer generates stenotype that is transformed into captions by computer software. Due to technical limitations, real-time captioning does not allow the captions to be properly placed under the person speaking. They roll up from the bottom of the screen. In addition, the presentation rate (number of words appearing per minute) and language level (related to reading level) cannot be controlled with real-time captions. When generating real-time captions, the presentation rate is dependent upon the speech rate of the speaker with whom the stenographer is forced to keep pace. In contrast with the off-line process, real-time captions allow for little editing and produce a (primarily) verbatim text. Due to problems inherent in stenotype translations, text errors do appear in the captions. The accuracy and delay time of real-time captions have improved between the mid 1980's to the mid 1990's. In 1987 the accuracy rate was approximately 95% with a skilled operator, and there was a 4-second delay time from speech to on-screen print (Carney & Verlinde, 1987). In 1995, the Caption Center tests real-time stenographers for 98% percent accuracy and a 1 to 3 second delay time, while NCI tests for 97% accuracy and a 3 to 4.5 second delay time.

**Live display.** With live display, the captions are produced off-line, but generated live (Salomon & Freda, 1992). When turn-around time between postproduction and broadcast is limited, the captioner has time to get a script or audio tape of the program in order to create
the captions. The captions are put into a computer file with the captioning software prior to the broadcast. During the broadcast of the program, the previously created captions are rolled up live by the captioner. A court reporter is not involved.

Some of the same problems found with real-time captioning are present with live display. The language level and presentation rate are not controlled because there is not enough turn-around time for editing. Similar to the real-time process, live display caption text is primarily verbatim. An advantage of using live display is that text errors can be cleaned up prior to broadcast. This eliminates the errors that are commonly found with real-time captioning. Unfortunately, a delay time still exists, but it is less than that found with real-time captioning because there are fewer factors that cause delay with live display. Also, like the real-time system, live displayed captions are not properly placed under the speaker. They roll up from the bottom of the screen.

**Newsroom computer captions.** Newsroom computer captions are used for news programs that utilize a teleprompter (a screen that displays the script for the newscasters to read during the broadcasting or recording of the program.) This captioning system is part of a larger computer system that controls many components of a newsroom, including: (a) writing and editing of news stories, (b) creating a computer script file that generates the teleprompter text and the closed captions, (c) generating the station logo on screen and character generated titles (that typically identify a speaker), (d) controlling the camera from the control room, (e), rolling prerecorded videotape, and (f) keeping schedules for newsroom personnel.

The newsroom computer captions system involves the use of a computer software program that sends previously prepared teleprompter text simultaneously to a teleprompter and to a closed caption encoder (Salomon & Freda, 1992). The encoder then places the captions in the vertical blanking interval used to transmit closed captions. Similar to real-time and live display captions, newsroom computer captions are not properly placed under the speaker. Roll-up captions are used, and the text is primarily verbatim.
The captions are pre-typed and rolled during the broadcast by a teleprompter operator. As the captions are not created in reaction to hearing speech, as is done with real-time captions, captions may appear before, during, or after the speaker. The synchronization can vary from story to story or within a single news story.

There is not a separate operator to run the closed captions, as they are generated automatically as the teleprompter script is rolled. The ability to have one operator for both captions and teleprompter is one of the main selling features for adopting this captioning system. The priority for the teleprompter operator is to roll the teleprompter script computer file in a manner that will allow the anchor to read text as it appears at the center of the teleprompter screen. This causes the captions to appear slightly behind the speech. The operator pays marginal attention to the closed caption function. A skilled teleprompter operator can make the captions appear close to the speech, while maintaining an appropriate pace for the anchor. An unskilled operator can cause the captions to occur way ahead or behind the speaker. Inept operation can also cause the system to crash or lock up and result in the loss of captions for a significant period of time. (Normally the system cannot be turned off and on again until a commercial break, because shutting off the system would cut off the teleprompter for the anchor.)

One unique limitation of this system is that only teleprompter text can be converted to closed captions. Weather reports, ad-libbed chit chat, and deviations from the teleprompter script are not captioned. Video segments with pre-recorded speech are also left uncaptioned unless the text is typed into the teleprompter script and shown on the teleprompter during the broadcast. If the text is not in the teleprompter script, then it will not appear in the captions.

Character Generated Captions. A character generator is a component of most television studios. Its chief purpose is to create brief subtitles that identify speakers during a television program. Although character generators can be used to create captions, they are rarely used for this purpose. The primary reason is that they cannot create closed captions, only open
Character generated captions typically pop-on, but some have roll-up capabilities. The pop-on captions can be placed directly under a speaker. The captions are keyed in ahead of time and punched or rolled up manually while a pre-recorded tape is rolling or during the videotaping of a pre-scripted program. The more expensive devices can use a computer software program to set the captions while the videotape is rolling.

Top-of-the-Line Character Generator

Although, it is possible for a top-of-the-line character generator to generate quality open captions, character generated captions are rarely used by network television broadcast stations and videotape productions because they can generally afford captioning software and an encoder or an outside captioning service. Also, few broadcasters or videotape producers would be willing to generate open captions, because some hearing viewers object to them, and they could lose viewers and advertising revenue.

Unfortunately, when character generated captions are used, they are typically used by low-budget organizations because they already own a character generator and can't afford a closed captioning system or the services of an outside captioner. Organizations that create character generated captions tend to have low-end equipment. Low-end devices typically have the following limitations and problems:

1. The captions must be punched up or rolled up by an operator during the taping of a program. There is a great amount of room for human error, as each caption is punched up in reaction to the speech of the performers or announcers. The captions might be punched up ahead of time or after the speaker. There would likely be a great amount of inconsistency with the timing within a given segment.

2. There is no time code capability, and the captions will likely be out of sync.
3. The caption text storage space in the character generator tends to be quite small and only holds a few minutes worth of captions. Captions for a long segment could not be held in the character generator. When the text runs out, the videotape needs to be stopped and new captions for the next segment need to be typed in to the character generator. Then the videotape could be restarted and another segment could be captioned. Starting and stopping a videotape while laying out captions might result in jumps in the captions, audio, and/or picture.

4. The open captions generated by a low-end device tend to resemble those used for foreign films that feature white letters with no background or shadowing. If the program has a white background (e.g., a snow scene), the captions can blend in and become hard to read.

Choice of systems. Although high-end character generators can create acceptable captioning, they are not used by broadcast television stations because the captions would be open. Open captions are not acceptable practice, with the exception of a few children's shows that are currently being open captioned to improve reading skills of hearing children. Some universities with tight budgets and mom-and pop television stations might have no other option than to use a low-end character generator to create captions. As newsroom computer captions are primarily used in broadcast news productions, that system is rarely considered by producers of other types of programming (Salomon & Freda, 1992). With the inferior quality of real-time captioning, it is not surprising that this system is normally used only for live broadcasts, such as sporting events (Gallaudet, 1992). Live display is used when there is a limited turn-around time from post-production to broadcast. This is used primarily for talk shows and soap operas. As live broadcasts and limited turn-around time productions constitute a small percentage of television programming, off-line captioning is the most frequently used system. Most non-live television productions and rental or sale video cassettes contain captions that are produced off-line.
Closed vs. Open Captions

Closed captions. Closed captions are encoded on Line 21 of the vertical blanking interval of the television signal (Gallaudet, 1992; Salomon & Freda, 1992) and remain invisible unless a decoder is connected to the television set, the cable converter, or other tuning source or a decoder chip is part of the television circuitry (National Captioning Institute, 1991; Salomon & Freda, 1992).

Open captions. Open captions are placed directly onto a videotape without encoding. A decoder is unnecessary when viewing these captions (Gallaudet, 1992).

Choice. Availability of a decoder box or a television with a built-in decoder chip is the major issue in deciding whether to use open or closed captioning (Gallaudet, 1992). In consideration of those hearing individuals who object to open captions, television broadcasts and pre-recorded videotapes for sale or rent normally use closed captions (Gallaudet, 1992). There are situations, however, when open captioning might be necessary. For example, some classrooms and public establishments need to have videotapes produced with open captions because a decoder is not available. Training and promotional materials are often produced in this manner, because the availability of a decoder from site to site is uncertain.

Pop-on vs. Roll-up captioning

Pop-on captions. With pop-on captions, each new caption appears and then disappears (Gallaudet, 1992; Salomon & Freda, 1992). Captions pop on at the left, right, and bottom center of the screen to indicate the physical location of the speaker (Verlinde & Schragle, 1986). Off screen narration normally is indicated by the use of italics and/or is displayed at the top of the screen.

Roll-up captions. Roll-up captions continuously scroll up from the bottom of the screen (Gallaudet, 1992; Salomon & Freda, 1992). There are typically three or four full lines on the bottom on the screen. A new line rolls up from the bottom and replaces the top one. With
this system, the captions are not placed directly under the current speaker. This makes it
difficult for the viewer to determine who is speaking at any given time, unless the speakers' names are included at the beginning of each line of dialog.

Choice of methods. The choice of pop-on or roll-up captions is normally connected to
selection of the captioning system (off-line, real-time, live display, newsroom computer
captions, or character generated captions) (Gallaudet, 1992; Salomon & Freda, 1992).
Character generators typically create pop-on captions, but some can generate roll-up captions.
Although the real-time, live display, and newsroom computer captions systems are limited to
the use of roll-up captions, there is some flexibility afforded by the off-line system (Computer
Prompting and Captioning Company, 1993). The off-line software will allow the captioner to
use either pop-on or roll-up captions. Whenever possible, pop-on captions should be used
because they allow for better understanding of the videotape, as the physical location of the
current speaker is made clear to the deaf or hard-of-hearing viewer through caption
placement. When roll-up captions are used with an off-line system, they are quicker to
generate, as the captioner is not required to make judgements about caption placement.

Verbatim vs. Edited Captions

Language level and presentation rate. Before discussing verbatim and edited captioning, it is
important to review presentation rate and language level as two factors that influence the
choice of these captioning methods. The presentation rate is determined by the number of
words per minute appearing on the screen, while the language level is established primarily
through the grade level of the captioned text (Braverman, 1980; Braverman & Hertzog, 1980).

Captioning professionals have developed standards for presentation rates, although the two
major captioning companies, NCI and The Caption Center, are not in agreement. The
presentation rate for off-line captions for adult programming is approximately 180 words per
minute for the Caption Center and 120-150 word per minute for NCI. Children's shows use a
lower presentation rate of 80-100 words per minute for NCI and 80-120 words per minute for
The Caption Center. All of the above rates are for off-line captions. For real-time captions, the Caption Center reports a presentation rate of 180-200 words per minute, while NCI estimates approximately 180-220 words per minute.

Presentation rates are not difficult to determine. Captioning software is capable of displaying the presentation rate for each line of text. This software counts five characters (including internal spaces and punctuation) as one word.

The language level is normally simplified only when the viewing audience primarily consists of children or adults with low reading ability. A review of the literature revealed three models that provide guidelines for editing the language level and presentation rate of captions for television programs (Braverman, 1981; Montandon, 1982; Shulman & Decker, 1979). For these models, multiple levels (e.g., Level 1, 2, and 3) were differentiated by (a) the complexity of the grammar structure, (b) the vocabulary grade level, (c) the use of English idioms, and (d) the presentation rate. With an understanding of language level and presentation rate, it is now possible to discuss verbatim and edited captioning.

Verbatim captions. Strict verbatim captioning results in an exact transcript of uttered speech (give or take a few words). Loose verbatim captioning is a process that retains close to the exact utterances while omitting many superfluous words. Omissions with loose verbatim captioning are done solely for the purpose of reducing the presentation rate. For example, a speaker might be talking rapidly, and words might be eliminated to lower the amount of captions appearing on the screen. Editing to lower the language level is not done with either strict or loose verbatim captioning. Newsroom computer captions use strict verbatim captions because they are generated directly from the script that is read by the newscasters. Real-time captioning and live display systems use strict verbatim captioning, due to the lack of time to edit the captions. With real-time or live display, occasionally a word or two is cut when there is a very rapid speaker. Loose verbatim captions are more commonly found in off-line
captioning or character generated captions, where not every utterance is captioned on the screen.

Edited captions. Edited captions are those that reduce the language level as well as the presentation rate. Montandon (1982) discussed two approaches to edited captioning. One approach is the intuitive approach. This is based on common sense and not on standard guidelines. Grammar and vocabulary is simplified, sentences are shortened, and idioms are rewritten. One major limitation of this method is that only one captioning level is available. With the second approach that uses strict standards and guidelines for editing captions, it is possible to use multiple language levels.

Choice of verbatim or editing methods. Strict verbatim captioning is highly undesirable with its high presentation rate and language level and should be avoided if possible. It is necessary to use strict verbatim captioning when using a real-time, live display, or automated newsroom captioning system. Strict verbatim captioning is not acceptable when the production is not live or does not have a limited turn-around time. For off-line captioning or character generated captions, only loose verbatim or edited captions are acceptable. Loose verbatim captions are selected when the language level is not an issue, but the presentation rate needs to be lowered. This method is generally used for captioned viewers who function at a normal reading level. Edited captions are used when both the presentation rate and language level are an issue. Editing captions should only be used with specialized populations, such as children or adults who function at low reading levels.

Editing
When editing is done to reduce presentation rate, consumers should expect intelligent editing. For a general audience, only superfluous or repeated words should be eliminated to reduce the presentation rate. Paraphrasing and elimination of large phrases or sentences is unacceptable. The consumer should not tolerate the censoring of sexual language, a practice that is rarely done today, but was commonly used for the Caption Films for the Deaf project.
With an understanding of the different captioning systems and methods, it is now possible to discuss reasonable expectations of quality standards for each system.

**Expectations of Quality Standards**

**Off-Line Captions**

If a captioner is using the off-line system to the best advantage, the following can be expected. The captions should be:

1. Timed to change with the shots or speaker. There should be no delay time. If there is a pause in the dialog, captions can appear a brief moment before a speaker to allow more time to read them.

2. Pop-on style placed under the speaker. Roll-up captions should not be used with this system.

3. Error free. You should not see any typos in off-line captions.

4. Edited minimally to reduce presentation rate, not language level.

If these expectations are not met, the consumer should complain to the broadcaster, producer, or captioner. Care should be taken to use the SMPTE time code feature to time the captions. Captions should be carefully placed and proofread. A few superfluous or repeated words should be edited out to reduce the presentation rate. For a general television audience, the captioners should not do extensive editing or rephrasing to lower the language level with the exception of children's programming.

**Real-time Captioning**

If the real-time method is being used to its best advantage, the following should be expected:

1. Captions should appear no more than 3 to 4 seconds behind the speaker.
2. Roll-up style should be used. The paint-on method is necessary to reduce delay time.

3. The error rate should be no more than 3% of the total text.

4. Strict verbatim captioning should be used with only a few words edited out if the court reporter is falling behind. Editing to reduce presentation rate is not feasible with this system because it would result in more thinking time for the reporter, which would increase the delay time.

If the delay time is too long or the error rate is too high, this may indicate that the court reporter is not skilled enough to adequately perform this function. Consumers should complain when poorly skilled reporters are used.

Live Display
For live display captions, if the system is used properly, the following can be expected:

1. The captions should appear no more than 1 or 2 seconds behind the speaker.

2. Captions should be roll-up style. The delay time is not sufficient enough to warrant using the paint-on method.

3. Captions should be error free.

4. Strict verbatim captioning with only a few edited words should be used.

Editing to reduce presentation rate is not feasible with this system, because there is limited turn-around time that does not allow for editing decisions to be made. If the delay time is too long or the captions contain errors, consumers should complain to the broadcaster.
Newsroom Computer Captions

The newsroom computer caption system has the most variability in proper use or misuse of this system. This is one system that has the most potential for consumer advocacy, as most newsrooms do not use it to its best advantage. Even with its best use, not all news segments are captioned.

What Can be Requested and Expected by Consumers

The following quality standards can be expected with the newsroom computer captions system:

1. The captioning system does not constantly lock up and cut off, which would result in the loss of captions. If this problem exists, the newsroom may have either inferior software or malfunctioning or limited computer hardware.

2. All production cues should be omitted. Production cues are for the director and include phrases like, "AD LIB WEATHER," "TOSS TO SUSIE," or "2 SHOT MIKE AND DAVE." These are typed into the teleprompter script, but can be cut out of the captions by using special coding for these directions, such as surrounding braces.

3. Most pre-recorded stories should be captioned. Viewers can strongly urge the newsroom producers to caption these stories if they are not precaptioned.

4. Captions should not linger during uncaptioned segments. While an uncaptioned segment is being taped, the captions for the next captioned segment will "sit" on the screen if the captions are not turned off. Captions should be turned off promptly when an uncaptioned segment is beginning and promptly turned back on when a captioned segment is beginning.
5. Newsroom captions should not linger during commercial breaks. If the newsroom captions are not turned off before the beginning of a non-captioned commercial, the last newsroom caption can linger on the screen during the commercial. Captions should be turned off promptly when going into a commercial. (If the commercial is captioned, the captions will already be encoded and turning off the captions on the newsroom system will not affect them.)

6. Captions should be turned on promptly after coming back from a commercial break a non-captioned segment.

7. Captions should appear close to the speech, give or take a brief delay time.

8. Captions should have a low percentage of grammatical, spelling, and typographical errors. At minimum, the reporters, producers, and anchors can use the spellchecker that is available on the teleprompter script software.

9. The captions should be Roll-up style.

10. Verbatim captions should appear for all segments that are read live, unless the newscaster strays from the script.

11. Verbatim captions should also appear on pre-recorded segments, but a few superfluous or repeated words might be edited out to reduce presentation rate.

**Unrealistic Expectations (Especially for Small TV Stations)**

1. Captioning of Ad libbed chit chat between anchors.

2. Captioning of the weather.

3. Captioning of breaking reports from the field.

5. Captioning of live contests, such as lottery drawings.

The captioning of the above-listed segments would require a court reporter and a live captioning system in addition to or in lieu of the newsroom captions. A small station might not be able to afford this, but a large station might be convinced to hire a court reporter.

**Character Generated Captions**

This system is rarely used to create captions by a broadcaster or caption producer because it cannot create closed captions. One exception is the use of this system to create open captions for the Caption Films for the Deaf project. The Caption Center in Boston uses this system because they have been requested to create white shadowed captions with no background, which cannot be created with other captioning systems that use an encoder. They no longer are captioning films for this project, but are captioning videotapes.

**High-end character generator.** When a high-end character generator is being used, the expectations for the quality of captions are almost identical to those for closed captions used with an off-line system. Captions should be:

1. Timed to change with the shots or speaker. There should be no delay time. If there is a pause in the dialog, captions can appear a brief moment before a speaker to allow more reading time.

2. Pop-on style placed under the speaker. Roll-up or paint-on captions should not be used with this system. Although roll-up captions are typically used with character generators, there is no reason that roll-up captions should be used with a high-end character generator, because it has the pop-on capability.

3. Error free. You should not see any typos in off-line captions.
4. Edited minimally to reduce presentation rate, not language level.

5. White captions on a black background or shadowed white captions with no background. The selection of white on black vs. white shadowed captions is a matter of audience preference.

Mid-priced and low-end character generators. Mid-priced and low-end character generators are only used by low budget stations and universities to create captions. There is such a variety of features on different character generators that the consumer would have difficulty knowing whether a particular character generator is being used to its best advantage. The best a consumer can do is suggest changes to the captioning and find out if these changes are possible with the equipment being used. A consumer could have the following minimal expectations from a low-end character generator:

1. A skilled operator can punch up the captions in a manner that would cause them to be reasonably in sync with the speaker.

2. The captions should be free from errors, as they are prepared ahead of time.

3. The captions should be pop-on style. (Most of the cheaper systems are limited to this style.)

4. Every attempt should be made to ensure that white captions are not fading into a white background.

Consumers should complain if the captions are way out of sync and contain typos. If the captions are fading into the background, a request should be made to use any kind of shadowing or background available, keeping in mind that some very cheap character generators do not have these features. If a caption producer or broadcaster that is not operating on a shoe string is generating captions on a cheap character generator, a request should be made that another system be used.
SUMMARY

There are five captioning systems currently in use. The system of choice is typically dictated by the television program content. Each system has its own quality standards determined by the captioning industry and the system's limitations. It is important for the consumer advocate to consider the limitations of each system, prior to asking for improved captions. An advocate would lose credibility if he or she asked for something that was impossible to deliver. For example, it would be unrealistic to expect pop-on captions without delay time in a live television program.

The two questions stated in the introduction section provide guidelines for the early steps of advocating for quality captions. First, the consumer should determine which system is being used, then determine whether the system is being used to its best advantage. If the consumer determines that the broadcaster or home videotape producer is not providing the best quality captions available, then there is good reason to request improvement. Understanding the workings of the individual captioning systems will help the consumer to make intelligent suggestions for improvement. It might be more effective to offer such suggestions, rather than only offering complaints. The ability to make an informed request for quality captions will hopefully go a long way toward obtaining a higher level of quality captions viewed on broadcast television or home videotapes.

References


NOW YOU SEE IT, NOW YOU DON'T: COPING WITH AGE-RELATED VISION LOSS
Martha Bagley & Laura Thomas-Roebal

Age brings with it a number of physical changes that are completely normal and the risk of others that are not. Experiencing these changes can be disconcerting and even frightening. Coping with them can be a challenge. Successful adaptation to age-related physical changes can influence a person's sense of well being and overall satisfaction with life.

Some of the most common age-related changes experienced are in the area of visual functioning. Normal age-related vision changes are commonly referred to as presbyopia or "old vision." Vision loss can also result from age-related disorders that are definitely not normal, but more likely to occur in people over 65. It is very important to understand the difference between normal and abnormal vision changes and to obtain good regular vision screening. The most common age-related changes in visual functioning are:

- increased sensitivity to glare
- increased need for light
- slower distance accommodation
- slower adjustment to different light conditions
- reduced contrast sensitivity
- reduced hue discrimination
- reduced peripheral or side vision
- dry eye.

These "normal" changes in visual functioning can cause significant problems with everyday activities, especially when they are combined with another sensory loss or any one of a number of chronic physical problems associated with age. These "normal" vision problems can cause significant communication difficulties for a person with hearing loss. Therefore,
any questions about what might or might not be normal visual changes should be discussed with an eye care specialist.

The leading causes of late-onset blindness among older adults are cataracts, age-related macular degeneration, and glaucoma. Cataracts are a problem of the lens that prevents light from reaching the back of the eye. Simple surgery to remove the cloudy lens will correct the problem. Glaucoma has to do with the pressure inside the eye. A simple, painless test can detect early problems and medications or a simple surgery will prevent loss of peripheral vision. Macular degeneration involves the nerve cells within the eye that account for our clear central vision. This disease causes a loss of vision in the very center of the visual field. Anyone who has a systemic disease like diabetes or hypertension should regularly visit an ophthalmologist.

There are two types of vision with which you should be familiar. First, an acuity loss occurs when an individual is unable to clearly see the details of an object. A person with a visual acuity of 20 over 200 (20/200) must be 20 feet from an object to see what an unimpaired person would see 200 feet from the object. Second, a field restriction means that there are areas within the field of vision (as far as you can see from side to side and up and down while looking straight ahead) that cannot be seen. Blindness occurs when a person is unable to see anything or when the remaining useful vision is so limited that it does not provide any useful information about the environment.

Regular eye examinations by an ophthalmologist or optometrist are recommended once a year for everyone over the age of 40. Such examinations will help identify vision problems early so that they can be appropriately treated.

An Ophthalmologist is a doctor of medicine who specializes in all aspects of eye and vision care. In treating eye conditions, An Ophthalmologist can prescribe medications and perform surgery. He or she is also able to prescribe glasses or contact lenses based on an eye
examination. An Optometrist is licensed and specializes in determining the need for glasses and identifying abnormalities of the eye. An Optometrist can not perform surgery. An Optician is licensed to fit, adjust, and dispense glasses or other optical devices on the written prescription of an Ophthalmologist or Optometrist. When visiting your eye care specialist, it is a good idea to ask specific questions that will help you understand any changes in visual functioning or eye diseases that you might have.

There are a number of easy accommodations that can be made to deal with the effects of presbyopia. These accommodations include:

- turn on more light
- use both task and overhead lights
- wear sunglasses, caps or sun visors
- regularly clean glasses and car windshields (on both sides!)
- use non glare or matte surface paper
- write larger, with a dark felt tip pen
- turn your head when scanning a room or crossing streets
- use reading or bifocal glasses
- use contrasting colors to make objects in the home easier to see
- be organized and systematic.

People with greater vision loss from an age-related eye disease may need to use additional accommodation strategies, such as:

- obtain large print books
- use magnifiers
- use large display TTYs
- use writing guides.

Significant vision loss may also require changes in communication techniques. People who are late-deafened and have visual impairments must assert themselves in communication situations. For communication to be successful it is important to be able to tell others what
you need. "Bluffing" or settling for less will cause the communication situation to be frustrating and eventually break down. It is important to be specific when talking to other people about communication needs and to identify areas that can be controlled. It is not only appropriate but important to ask for better lighting, a quieter room or fewer distractions.

Communication becomes more difficult when a person who is late-deafened acquires a vision loss. For example speechreading may become harder as faces become less easy to see. It may also be necessary to make modifications in the way signing is used. It will also be important to pick an appropriate place to communicate. For example, tactile signing will require the people communicating to sit close together. In some cases it maybe necessary to step further back from a person with a restricted visual field so they can see more of the signs. What the person who is signing wears is also important. With some visual conditions, a dark background is easier to see. Depending on the visual condition it might also be necessary to restrict signing to a small area within the visual field, and use tactile signing, by placing the listener's hands over those of the person signing to you.

Deaf-blind is a term that can be intimidating and it is very different from late-deafened/visually impaired. The two terms have different emotional connotations. It is not necessary to call oneself deaf-blind in order to successfully cope with a hearing and vision loss. Each person's experience is different. What is important is being confident enough to do what is necessary to communicate and to do the other tasks necessary to live happily from day to day.

There are resources available. By connecting with agencies and organizations, ALDA and its membership can build a network of support. The American Association of Deaf-Blind (AADB) is one organization made up of all types of people with different levels of hearing and vision loss. They come together regularly for conferences that have both an educational and social component.
The Helen Keller National Center (HKNC) can provide information, services and support. There are 10 Regional Representatives across the country that can be contacted for information and assistance. To find the Regional Representative serving your area contact the Helen Keller National Center, 111 Middle Neck Rd., Sands Point, NY, 516-944-8900 (voice/TDD).

There are also a number of agencies that can offer assistance and information about vision loss. They include:

National Association of the Visually Handicapped
22 West 21st Street, 6th Floor
New York, NY 10010
212-889-3141 (V)

American Foundation for the Blind
11 Penn Plaza, Suite 300
New York, NY 10001
800-232-5463 (V) 212-502-7662 (TTY)

Prevent Blindness America
500 East Remington Rd.
Schaumburg, IL 60173
312-843-2020
Most of us could benefit from learning to approach everyday life situations using a systematic model of interpersonal problem solving to obtain our goals. This workshop is designed to provide an overview of this model. It is based upon research conducted at the University of Arkansas Rehabilitation Research and Training Center for Persons Who are Deaf of Hard of Hearing that resulted in the development of the Interpersonal Problem Solving Skills Training Curriculum (Boone & Johnson, 1991). This approach presents a systematic strategy to obtaining goals in social situations.

Initiated in 1986, the research that underlies these materials included a national survey of rehabilitation, independent living, and community service center programs to determine the kinds of skills training materials that would be of use in working with consumers who are deaf or hard of hearing. About 80 percent of the programs surveyed identified the need for materials for teaching their consumers how to problem solve in interpersonal situations. Based upon this need, we developed and tested materials to assess people's interpersonal problem solving skills as well as ways to teach people to improve these skills. This curriculum is currently in use in a number of programs around the country.

This workshop will focus on the content included in this curriculum. The goal is to interactively provide you with the opportunity to gain some insight into research proven strategies for effective problem solving in social situations. This exposure will enable you to develop these skills.

Background

The problem solving approach builds upon research initiated in the seventies in the area of assertiveness training. The goal of assertiveness training was to teach ways to respond in
problematic interpersonal situations that would be more likely to result in people obtaining their goals. The skills and behaviors taught included specific categories of responses (i.e. initiating requests, refusing unreasonable requests) and the specific behaviors (i.e. posture, eye contact, speech fluency, and pacing). By using these responses and behaviors, persons were more effective in obtaining their goals. In fact, effectiveness of behavior in obtaining goals was shown to vary depending on how assertive persons were. People who were very passive or submissive didn't seem to accomplish their goals when compared to people who were assertive. Similarly, persons who were overly aggressive also didn't accomplish their goals when compared to those who were assertive.

A substantial body of research demonstrated the utility of these approaches. Participants in the training would learn the targeted skills and if they used them, they would tend to be more effective. Unfortunately, over time we began to learn that many persons found it difficult to implement these strategies outside of the situation in which they were learned. Furthermore, if people only responded using an assertive strategy, it was often difficult to know when to be assertive or what to do if this response did not work. These and other similar limitations of the approach led to an expanded model of skills training known as interpersonal problem solving.

**The Interpersonal Problem Solving Model**

The approach to problem solving includes a number of specific skills to assist persons to overcome interpersonal problems and to obtain one's goals. The problem solving approach includes six basic steps:

1. Problem Orientation
2. Problem Identification and Description
3. Generating Solutions
4. Evaluating Solutions
Implementing Solutions
6. Verifying Solutions.

Each of the six steps is critical to the process of becoming a skilled problem solver. They can be learned and applied in a step by step way to obtain your goals. The remainder of this presentation presents an overview of specific guidelines for each of these steps.

Guidelines for Effective Problem Solving

1. Problem Orientation

When you initially try to approach problematic situations, it is critical for you to know what your goals are. Obtaining most of our goals require some sort of social interaction. For example, if you want to get an accommodation at the job, maybe some new technology, you have to make a request and interact with someone in order to obtain this technology. In each social situation you must interact and know what your goal is in order to accomplish it.

Although we are not going to discuss the skills required to identify goals, the general principle is to define your goals clearly and on a continuum of realism. Even if your goal is huge, break it down into steps that will get you there. For example, I remember working with a young man in California who wanted to get married, a reasonable "social" goal. He identified a number of steps along the way to this goal, starting with simple steps of identifying and asking someone who was interesting out for a cup of coffee. Now that's clearly a long step from getting married, but it is a critical step along the way.

The second part of problem orientation is to believe that you can overcome obstacles that prevent you from accomplishing your goals. Some people find it difficult to view themselves as being able to resolve or overcome barriers to their goals. Many times, persons feel barriers are insurmountable, and they refuse to try to accomplish their goals. Believing you can overcome these obstacles is critical to obtaining goals.
Finally, you must also stop and think in problem solving situations before you respond. Often, people behave habitually in problematic situations, and therefore miss the opportunity to accomplish their goals by responding in less than appropriate ways. Prior to responding, stop and think "Does this lead to my goal?"

2. Problem Identification and Description

Problem Identification and Description is the second step in the problem solving process. In order to solve problems, persons must accurately perceive the relevant parameters of the problem before they act. A number of questions may be used to identify the key aspects of the situation. Who is in the situation? What is happening? Where is it happening? When is it happening? An adequate description is necessary to help you define the specific interpersonal obstacles that are preventing you from accomplishing your goal.

For persons with a hearing loss, identifying and describing the problem is often especially problematic. Many persons are simply unsure if they have accurate clear communication. In many cases it is difficult to control extraneous factors in the situation that impact on communication. For example, background noise, insufficient lighting, and malfunctioning assistive technology may impact on your ability to understand what is happening. Think through ways to manage the communication situation and be creative in exploring various alternatives to help you define the obstacles in each situation.

3. Generating Solutions

The third step in problem solving is generating solutions, or alternatives, to use to solve the problem. In contrast to the approach advocated by assertiveness training (i.e., where you would always try to be assertive), this model advocates generating a range of potential solutions. This process is guided by two well-researched principles.
The first principle is the notion that "quantity breeds quality." Come up with as many possible ways to respond as you can. The more you identify, the more likely you will come up with a solution that will help you accomplish your goal. At minimum, the process of generating a number of alternatives will allow you to form a multiple step plan toward your goals.

The second principle guiding the generation of alternatives is to "defer judgment." When deciding what to do in social situations, many persons automatically rule out alternatives they could use to get to their goal. They automatically think, "I couldn't do that." But the literature is clear. Persons who defer judgement when identifying alternative solutions will ultimately be more effective problem solvers because they will have a broader range of alternative solutions available to them.

4. Evaluating Solutions

Once you have generated alternatives, you must evaluate and decide on the best solution. The way to evaluate solutions is to think of the advantages and disadvantages of each particular solution. Compare these and pick the solution that seems to give you the most advantages, minimal disadvantages, and the best chance of solving the problem. There has been a lot of research that helps people try to decide rules you might use for comparing and choosing. Unfortunately, it's not always simply the number of positive consequences outweighing the number of negative ones. We used to say that if an alternative had three advantages and two disadvantages, that's the solution you should try. But unfortunately that's not always true. Sometimes advantages and disadvantages have different weighting for different people. Some solutions are harder than others to implement. Some may have consequences that are personally what I call "killer" consequences. I would never choose that alternative because it would violate my principles and my beliefs. So you can't just say the positive ones outweigh the negatives ones because you may have to weigh them. But in
general, if there are more positives it will likely lead to your goal. If there are more negatives and it's not going to lead to your goal, obviously that's not the best choice.

5. Implementing Solutions

Once you decide on a strategy, then you put it into action using those basic assertive principles. We know from the literature that what you say and how you say it both make an impact. The content of your response or solution and the specific form or behaviors that you use are both critical.

Content. A number of guidelines have been suggested regarding the content of a response. Say for example that you are making a simple request. The research indicates that effective content is specific and concrete, and clearly helps the other person understand your goal. It also helps if you are reasonable. People tend to comply with requests that are reasonable given the situation. If you are asking for something, highlight how it will work for both of you, how it will help both of you. Highlight your shared needs. If your strategy does not work, step back, think of other alternatives that you have identified, and proceed. Also, prevent refusals by establishing a strong relationship with the person you are approaching.

Behavior or Form. A number of specific behaviors have been shown to be related to effectiveness in accomplishing ones goals. These behaviors include posture, eye contact, appropriate facial expression, and pacing of your response. Many persons with hearing loss comment that some of these behaviors are more difficult than others. Some persons find it difficult to make eye contact, especially if they are trying really hard to speechread. The key to effective eye contact is to avoid staring or pleading looks. This may be especially difficult to do this if you are trying to speechread. But remember, the person who is involved in the communication can't really tell if you are always making eye contact. Vary your gaze by looking at the persons forehead or chin occasionally. It is really hard to tell the difference.
Use animated facial expressions, ones that clearly convey interest. Once again, it may be difficult if you are really concentrating to demonstrate appropriate expressions. In any case, it is appropriate to vary your expression, to lean forward and to try to maintain pleasant and animated expressions in order to be effective. Pacing of your response is also related to effectiveness. Persons should avoid pacing that is exceptionally fast or slow. If your pace is really fast, it's virtually impossible to be understood. If your pace is too slow, it's equally difficult to be understood. So somewhere in the middle is the right way to pace a request.

Finally, response latency or the length of time you wait before you respond is also important. The research says that if you wait a long time before you respond, you tend to be viewed as inattentive or ineffective. Responding too quickly is equally problematic. For persons who have some hearing loss, response latency can be a key problem. Some people try to demonstrate they understand by trying one of two strategies. In situations where people are unsure if they heard correctly, they respond real quickly. If you wait a little bit, you have the opportunity to be sure you have understood. Avoid waiting a long time before you respond. Long response latency is seen as ineffective. If you require time to be sure you understood, one strategy is to respond in a timely way with a statement that buys you time to think. For example, you might state, "Let me think about that a minute" or perhaps "let me be sure that I understand". In either case you can cover the time lag. If you are unsure, it's always appropriate to request clarification or to state what you heard and let the person repeat parts that you may have missed.

6. Verifying Solutions

So we are going to put some behavior out there that is going to lead to our goal. In the old days, we would have been assertive and magically accomplish our goal, whatever that is. But, unfortunately, it just doesn't work that way. Despite your best effort, the environment doesn't always respond the way you want. Use that opportunity to evaluate your skills and decide on the next step in your plan. If you did a good job of generating alternatives, you
will have a whole list of ways to respond instead of just one. So evaluate your performance. Focus on your strengths, even if it is hard to do. People in our society do not usually focus on their strengths. Reinforce yourself for your achievements and success. Also evaluate what didn't work well, but focus this assessment on ways to improve, not just areas of weakness.

**Summary**

In summary, effective problem solving is the key to accomplishing ones' goals. These steps will provide you with a strategy to accomplish this task. Practice the series of steps until each becomes second nature and you will become more effective at obtaining your goals. Although you can't always ensure your success in obtaining your goals, you can clearly control yourself. Using these strategies will make you a better problem solver.

**Reference**

THE INTERNET AND E-MAIL: USEFUL TOOLS FOR PERSONS WITH HEARING LOSS

Roy E. Miller

Introduction

Throughout history the nature of the social world has always been partly a function of the ways in which people could communicate with each other over great distances. Certainly the world was never the same after the introduction of such telecommunication technologies as the printing press, telegraph, telephone, radio, and television. Without a doubt, one of the current telecommunication technologies which is presently reshaping the world is the Internet. As the primary computer based communication vehicle, it is changing how, when, where, and with whom we interact. There are many applications available on the Internet, but the one which is used most frequently is electronic mail (e-mail). These two telecommunication technologies, the Internet and e-mail, now play such a vital role in how the social, political, and economic systems of the world operate that everyone needs to understand the nature of these electronic beasts -- at the very least on an introductory level.

Beyond the fact that these two telecommunication technologies are playing an ever more important role in the world about us, these two technologies have some unique advantages for persons who are deaf or hard of hearing. Accordingly, there is a special need for such persons to become acquainted with these technologies. This paper aims to provide such an introduction, with the hope that what is presented here will be used much like the first step on a ladder -- something which merely gets one off the ground and started toward a higher and more useful level.

The material which follows will be presented as a series of basic questions and their answers. Given the frequently complicated and technical nature of the questions, the answers are often simplified in order to facilitate understanding.
The Internet: An Overview

What is the Internet?

What is called the "Internet" is really a network of computer networks, such as Fidonet, NSFnet, Usenet, Bitnet, Prodigy, America Online, Compuserve, Deaf-tek, and many many more. These networks vary in size, purpose, cost to the user and capability. In effect, the Internet consists of a collection of countless host servers (computers) around the globe. The number of host computers on the Internet is now estimated to be more than thirteen million, and is projected to number more than a hundred million by the year 2,000. These computers are of many different types, made by many different companies, and run a great variety of software. To enable these many different pieces of hardware to "talk" to one another they must have a commonly recognized set of instructions concerning how to address and deliver data that is to be sent from one computer to another. This set of instructions is called a "protocol" and what allows the Internet to function is the Internet Protocol (IP). So basically it can be said that the Internet is the worldwide network of all computer networks that use the Internet Protocol (IP) packet for sending data between computers.

How did the Internet start?

The Internet began about twenty-five years ago as a U.S. Defense Department network called the ARPAnet. The ARPAnet was an experimental network designed to support military research. In particular, the basic purpose of the ARPAnet was to develop a computer network that would continue to function even in the event of partial destruction by a nuclear missile attack. The basic premise of the network was that no one link in the network was reliable (it could be destroyed at any time), and the system must always be able to redirect data transmissions through whatever chain of computers was available at the given moment.
How big is the Internet?

The Internet is really big! It is a worldwide network consisting of more than a million separate networks around the globe. There are network nodes (computers) in over 50 countries, and there are an estimated 80 million Internet users with the number growing exponentially. Over 700,000,000 messages per month are sent over the NSFnet alone!

What can one do on the Internet?

There are lots of neat things that one can do on the Internet! To a computer programmer, all Internet applications fall into one of several basic types. For example, one can use what is called Internet Relay Chat (IRC). With IRC any number of people can log on at the same time, select a common channel, and carry on an interactive discussion. Everyone on that channel can see all of the discussion, but people on other channels cannot see the dialog. The channel may be setup either as a public channel or as a private channel. In effect, IRC is much like a telephone conference call or using a citizen's band radio (CB).

The File Transfer Protocol (FTP) allows a person to move files from one computer to another, regardless of where the computers are located, how they are connected, or what their operating systems are -- so long as they both "talk" the FTP protocol and have access to the Internet. FTP is most useful for retrieving files from publicly accessible archives scattered around the Internet (via so called Anonymous FTP). In effect, Anonymous FTP enables a person to access countless gigantic public databases around the world, search their contents, and retrieve information that is of interest. For example, one can access several different databases containing all of the regulations adopted by federal agencies to implement the Americans with Disabilities Act (ADA). And, if you are interested, you can retrieve a copy of whatever specific regulations you might want.

The Internet provides remote log in capabilities via TELNET. This allows a person with an appropriate account to access a distant computer the same as if it were "right at their
fingertips." For example, when I was at Gallaudet University in Washington, D.C. on my most recent sabbatical, I used TELNET almost daily to access and work on my "home" computer at Southern Illinois University.

There are several thousand discussion forums on the Internet in which one can participate -- either actively as a contributor or passively as a reader only (a so called "lurker"). These discussion forums are electronic communities where almost any topic one could imagine is discussed. Discussion forums utilize e-mail exploder programs (such as LISTSERV, LISTPROC, or MAJORDOMO), and their contents may also be followed by reading Usenet News (sometimes called NETNEWS). A couple of discussion forums that may be of particular interest to people who are deaf or hard of hearing are DEAF-L and BEYOND HEARING. I started DEAF-L in 1990 for the discussion of anything pertaining to deafness. On the other hand, BEYOND HEARING began more recently, and is a discussion forum more specifically focused on hard of hearing issues.

Although the basic functions performed over the Internet are instructive, it is often more interesting to think about what kinds of "real life" things one can do on the Internet. A list of such things would be both extremely long and ever growing, and would include shopping for almost anything, such as clothes, luggage, watches, jewelry, exercise equipment, household furniture, small appliances, records, books, and, of course, computers. The Internet can also be used for following the stock market and making investments, reading magazines and newspapers, making travel arrangements and purchasing airline tickets, getting the latest news, weather and sports information, watching movies, playing innumerable computer games, finding and downloading thousands of useful computer programs, reading everything that Shakespeare ever wrote, and obtaining a college degree without ever entering a classroom.
Where and how can one learn about the Internet?

One can learn about the Internet from many different sources. For example, you can get information about the Internet from friends, community college courses, magazines concerning computing, and any one of numerous books which have been written about the Internet, such as Ed Krolls "The Whole Internet." In addition, perhaps one of the best ways to learn about the Internet is on-line. Simply sit down in front of a computer with Internet access and get a "hands on" introduction using any of the network navigational aids that are available, including programs like Archie, Gopher, Veronica, the Global Network Navigator, Mosaic, or Netscape. Surf the Internet for awhile and discover its many uses, dimensions, and resources.

E-mail: Nature, Use, and Benefits

As I have mentioned, the largest single application on the Internet is the use of e-mail. While this telecommunication technology is basically very simple, it seems to be daunting and intimidating for some people. Hopefully the following brief discussion will answer some of the basic questions that many people have about e-mail, and in doing so will eliminate some of the fears that people might have in utilizing that technology.

What is E-mail?

E-mail is very similar to surface mail (so called "snail mail") with which we are all quite familiar. E-mail essentially is an electronic letter or message sent from one computer to another usually over the telephone network.
How does E-mail keep from getting lost?

The Internet uses a worldwide addressing system very similar to that used in the delivery of surface mail. For example, if one were to send me a letter by snail mail it would be addressed as follows:

Roy E. Miller  
408 Sycamore Terrace  
Carbondale, Illinois  
U.S.A.

That complete address consists of my name (Roy E. Miller), the specific house at which you want the letter left (408 Sycamore Terrace), the town in which the house is located (Carbondale), the state in which the town is located (Illinois), and the country in which the state is located (U.S.A.). All e-mail addresses consist of conceptually similar information. For example, the following address is for a friend of mine who lives in Israel:

Any e-mail sent to this address is for a person whose "user name" (sometimes called "screen name" or "user ID") is LEWGOLAN. Lew gets his e-mail "at" (indicated by the @ symbol) a computer (rather than a house) whose name is "CCSGII. That computer exists at Tel Aviv University (TAU), which is located on the academic network (AC) in Israel (IL). Technically each of these address components after the I@" symbol are referred to as "domains", and the domains run from the lowest (smallest) unit (the specific computer on which the person receives their e-mail) to the highest (biggest) unit (the country in which the computer is located). Originally the six highest level domains in the United States were as follows:

com Commercial Organizations  
edu Educational Organizations
One other thing needs to be remembered about e-mail addressing. If you live in France then you certainly have to put "U.S.A." on a letter which you are sending to the United States. However, if you live in Illinois then you don't have to put "U.S.A." on a letter which you are mailing to a friend in California. The same logic applies to e-mail. If the computer from which a message is being sent is in the same domain as the computer to which the message is being sent, then that component of the domain address need not be specified. For example, anyone in the United States could send me e-mail addressed to GEOO13@SIUCVMB.SIU.EDU, but would not need to include the "US" as the highest order domain.

What can you do with E-mail?

You can do lots of things with e-mail! For example, you can use e-mail simply to correspond with friends, associates, and relatives. Or if you are so inclined, e-mail is an excellent medium for doing advocacy work. You can write almost any national political figure including the President and all members of congress. E-mail allows you to network with most organizations serving people who are deaf or hard of hearing. You can use it to keep in touch with organizations like the Association of Late-Deafened Adults (ALDA), the National Association of the Deaf (NAD), Self Help for Hard of Hearing People (SHHH), Telecommunications for the Deaf, Inc. (TDI), and many more.

The use of e-mail can be a very productive way for geographically distant parties to engage in cooperative work. For example, co-presenters at ALDAcon who live in different parts of the country can easily develop their presentation using e-mail and never actually see each
other until their workshop begins. E-mail can facilitate all kinds of group document
development, such as position papers, committee reports, and newsletters. It is an excellent
tool for conference and program planning committees. For example, all discussion among
members of the ALDAcon 1995 Program Committee was done using e-mail. All kinds of
electronic meetings can be conducted using e-mail, and this makes it an excellent tool for
geographically dispersed boards of directors, such as the ALDA board of directors.

E-mail can be used to search for and obtain a wealth of information pertaining to hearing
loss. For example, using e-mail one can access data bases located at the National Information
Center on Deafness (NICD) at Gallaudet University, the National Institute for Disability and
Rehabilitation Research (NIDRR), the National Institute on Deafness and Other
Communication Disorders (NIDCD), and the National Rehabilitation Information Center
(NARIC).

In addition, one of the growing uses of e-mail is for a home-based business. For example,
persons who are deaf or hard of hearing can easily work at home in such areas as computer
systems consulting, desktop publishing, or investment counseling.

**Why is E-mail useful for persons with hearing loss?**

There are lots of reasons why e-mail is a useful medium for people with hearing loss. To
begin with, e-mail is a completely text based system of communication. That means that
persons with hearing loss are not disadvantaged in discourse with hearing persons, as they
usually are when that discourse is carried on orally. With the use of e-mail, there is no more
struggling with either limited signing or speechreading skills for persons who are late-
deafened or hard of hearing.

E-mail provides worldwide access, and that can be very important to a low density
geographically dispersed population like people with hearing loss. A person may be the only
A deaf person in a small town, or totally isolated in a rural area, but e-mail gives them access to others like themselves in many distant places.

E-mail is an asynchronous medium, which unlike the TTY does not require that both parties are present at the same moment in time in order to exchange ideas. Rather, with e-mail people can read or write their messages whenever their schedules, lifestyles, and mood permit. Given that the other party doesn't have to be available at the moment a person selects to read or write their mail, this makes e-mail convenient for everyone regardless of their work requirements, professional obligations, family and social needs, sleeping habits, and so forth. With e-mail, gone are the frustrations of playing "telephone tag."

E-mail is a self-paced medium and an individual can read and write their messages at their own speed. Gone are the days of trying to keep up with people who sign lightning fast, or trying to read a TTY message from a fast typist as it zips across the small screen, or forgetting the first part of a TTY message from an especially slow typist as that individual almost painfully picks out each character in every word. This helps to further reduce the amount of missed information in a message delivered by e-mail. E-mail is a reviewable medium. Unless you choose to dump it, an e-mail message is always there on your computer for you to check and double check again and again. Gone are the days when you dared not turn your head for a second as a TTY message scrolled off the end of the small screen never to be seen again. In fact, you can even fall asleep when reading a message, because it will still be there when you wake up!

E-mail can be sent from or received at almost any location. Unlike snail mail, which you generally receive only at either your home or your office, your e-mail can be accessed from almost anywhere, including your favorite restaurant, bar, or beauty shop, or in a motel while you are traveling. It used to be that if the place had a telephone jack then the e-mail user was in business. Now, with wireless phones and the proper hardware, one can access their e-mail from almost any mountain top in the United States.
E-mail is deliverable across vast distances. It can be sent to someone in England, Israel, or Australia just as easy as it can be sent to someone in the office building next door.

Communication by e-mail requires no expensive human interface. A deaf or hard of hearing person doesn't need to carry either an interpreter or a CART service provider in their pocket in order to engage in a dialogue with a hearing person -- as much as we love our human communication aides.

E-mail is unbelievably fast. You can generally communicate with someone half way around the world in a matter of hours or minutes, rather than waiting several days for your snail mail to be delivered.

With e-mail bad weather is no problem. If its raining or snowing you don't have to worry about walking to the mailbox or driving to the post office. Stay home, warm, dry, and comfortable, and send your e-mail from your fireside or bedside.

E-mail minimizes some communication barriers. For example, when communicating by e-mail you can't tell if the other person has green hair or a ring in their nose. Similarly you usually can't tell if a person is old or young, wears expensive suits or blue jeans, is male or female, black or white, deaf, hard of hearing, or hearing, or speaks with a New York accent or a southern Louisiana drawl. All of these social, lifestyle, economic, disability, and linguistic cues form communication barriers for some people, but those barriers are absent with the use of e-mail.

If you have family members, friends, or business people that you want to contact but they do not have e-mail access, this need not necessarily be a big problem. Depending on your e-mail service provider, you can also usually send or receive fax transmissions as well as snail mail with just the touch of a key or the click of a mouse.
For those of us who are concerned about the environment, the use of e-mail is ecologically quite desirable. If everyone used e-mail it could save millions of trees every year.

Finally, perhaps the biggest advantage of e-mail is its relatively low cost. There are so many different ways that people can now get e-mail access that it is impossible to say what it will cost someone. However, it is generally true that basic e-mail access will cost you less than your basic monthly telephone bill.

**So what's not to like about E-mail?**

There are a few things that would be considered negative characteristics of e-mail by some people. To begin with, a person must know the written language in order to be able to use e-mail (and that language is generally English). For most late-deafened or hard of hearing people this presents no big problem, but it can be a problem for some people whose native language is not English.

E-mail is a noninteractive communication medium. Accordingly, it lacks the immediate give and take of face to face communication and can require much longer to reach agreement among parties when disputes are involved.

To some, e-mail lacks spontaneity and is often referred to as a "flat" communication medium. As a result, it may not be the preferred medium for some people.

With e-mail there are few (if any) para-lingual cues as to the meaning of a message. Absent are the gestures, facial expressions, eye movements, and body language that often convey the emotional aspects of language, and thus, sometimes true meanings are all too easily misunderstood.
Given that the true meaning of e-mail messages can sometimes all too easily be misunderstood, people can sometimes react incorrectly or emotionally to misunderstood meanings. This so called "flaming" can be offensive or ego threatening to some people.

E-mail is a relatively high technology communication medium. It requires an investment in hardware and software which may be beyond the limits of some people's discretionary funds. In addition, many things can go wrong with electronic gidgets and gadgets, and repairs can sometimes be expensive.

The use of e-mail requires some computer literacy, and computers scare some people. Furthermore, the use of e-mail generally requires keyboarding skills, and this can be a barrier for some people.

What does one need to enjoy the benefits of E-mail?

The use of e-mail requires basically some hardware and some software. In particular, a person needs a personal computer (either Mac or IBM compatible) with a communications port (almost all personal computers have this), a modem (it can be slow or fast), a telephone line and jack (or wireless setup), a so called "mailer" program (given to you by your e-mail service provider), and e-mail access (an electronic mailbox).

How do you get access to E-mail?

There are numerous possible ways to get e-mail access. Some people get their access provided by their city, public library, local community college, university, or employer. Others obtain their own Internet gateway software and provide their own e-mail access. But by far most people purchase their e-mail access from a commercial on-line service provider, such as America Online (AOL), Compuserve, Genie, Prodigy, Deaf-tek, MCI-Mail, and many others.
Conclusion

I hope that in these brief pages I have been able to give you a better understanding of both the Internet and its most frequently used application, namely, electronic mail (e-mail). These two communication technologies are indeed changing the world in which we live, and a person should become familiar with them for that reason if no other.

The use of e-mail can be especially advantageous for people who are deaf or hard of hearing. Indeed, it can be a great enabler, providing an inexpensive and accessible communication medium where one's audiological status is of no concern -- and that's true empowerment for people with hearing loss.

Author's Note:

When this presentation was given at ALDAcon 1995 it included an on-line demonstration of the use of e-mail with AOL. That demonstration was done with the help of Steven Wilhelm and Terry Hockett, and their assistance is hereby gratefully acknowledged.
Carol Slaney: This is my first time at an ALDA convention, and I'm really happy to be here with all of you. I have had a lot of experience with SHHH. That's really been my support system throughout the many years of my hearing loss.

I graduated from Gallaudet University with a Master's Degree in Social Work. I entered Gallaudet with the intention of learning sign language, and I received a degree along the way. I have been a very strong advocate for deaf and hard of hearing people for several years. I serve on several boards of directors, including the Maryland Relay, Telecommunications for the Deaf, Inc., and Bell Atlantic. In addition, I am a past board member of SHHH. It's been a great experience, but I'm here to talk about cochlear implants.

More than 12,000 people worldwide have received a cochlear implant, and that number continues to grow day by day. In 1988, I attended my first panel concerning cochlear implants at a SHHH convention. I left there excited by the fact that there was a possibility for me to hear sound again. At that time I was not a candidate for an implant as I didn't have a severe enough hearing loss.

In 1989, I attended another SHHH convention in Washington, DC, and at that time I had lost more of my hearing. While there I talked individually to people with cochlear implants, and I left there in tears. They told me that they could hear music and birds, and that they were understanding speech. Some were able to use the phone again. I was just overwhelmed with the thought that maybe a cochlear implant would help me. Now I say that I have tears of joy because I now have a cochlear implant and can do all those things.

I'm hoping that this workshop will help some of you come to a decision as to whether or not a cochlear implant might help you, or some friends of yours. The question is, "Is the
cochlear implant for you?" I will give a brief history of the cochlear implant as well as explain how the implant functions and the nature of the surgical procedure.

There are two different companies that manufacture the most frequently used cochlear implants, namely, the Cochlear Corporation and Advanced Bionics. We have the representatives of those companies here with us today to answer questions about their products, the Nucleus 22 and the Clarion.

I'm not a medical specialist, nor am I connected with either of the companies that manufacture cochlear implant devices. I'm just here to help you make a decision for yourself. I will give you the background hopefully to enable you to make a good judgment. I will be talking about the criteria for candidacy, the cost, insurance coverage, what determines success, post-surgical rehabilitation, and how to make a decision as to which implant might be best for you. We will conclude with a panel discussion of personal experiences from several implant users.

The first cochlear implant research was conducted over thirty years ago in France. It may seem hard to believe that it's been around that long, but it took awhile to get to the level of success that it's now experiencing. It was first implanted in humans in 1972. The early implants were one channel implants. We now have as many as 22 channels with the Nucleus 22 implant.

In the Deaf community, there is a lot of opposition to cochlear implants. I was quite embroiled in the controversy at Gallaudet University, where a lot of the concentration has been on people who were implant failures or were disappointed with the one-channel device. That's part of the reason for the objection of the Deaf community to the implant. However, it is important to realize that the Deaf community is primarily against children being implanted, and doesn't really object to adults being implanted.
However, the situation with respect to children receiving the implant is definitely not so simple. What research findings seem to indicate is that children who are born deaf and implanted at a very early age are learning to speak, and they are learning to understand speech. Now, it took a while for research to show this, but it is definitely happening now. Partly as a result of these research findings, they are implanting more and more children. I know at Johns Hopkins Hospital in Baltimore they are implanting about 50 percent children and 50 percent adults.

For the adult who is either born deaf or prelingually deafened and implanted at an early age, there is not as much research showing success with the implant. So that's different, and that is something you have to think about. People who are post-lingually deafened are achieving the best results with the implant.

As I said, there are two major companies manufacturing cochlear implants, namely, Cochlear Corporation which makes the Nucleus 22 and Advanced Bionics which makes the Clarion. The FDA approved the Nucleus 22 for implantation in adults in 1985, and for children in 1990. The Nucleus 22 appeared in 1981, and it has gone through four major processor changes since that time. The Clarion implant has now been approved by the FDA for implantation in adults, but it's not yet approved for children. That will be the next step.

Now I'm going to show you a few slides from both companies so you can see what the two devices look like, and I will explain some of the basic differences. Figure One shows the human ear, and how sound normally enters the ear canal, causes the ear drum to vibrate, activates the anvil, stapies and stirrup bones, and is changed into electrical impulses in the cochlea. The implant, of course, goes directly into the cochlea.

Figure Two shows an item that looks like a hearing aid, but it is not a hearing aid. It goes over the ear and is the microphone. It transmits the sound to the processor, which is the little box. These items are the external parts of the system.
The microphone picks up the sound and sends it to the processor. The processor, of course, does just what its name implies. It processes the sound, sends the signals back up the wire cord to the round flat piece that is a magnet, and transmits the sound to the internal part. The internal part carries the signals and stimulates nerve endings in the cochlea.

Figure Three is the Nucleus 22, and it shows the actual electrodes. The 22 electrodes are inserted into the cochlea. The device is very flexible, very soft, and it stimulates the nerve endings. In no way is it anything like a hearing aid. This actually goes into the cochlea and stimulates the nerves. Figure Four slide shows the Clarion multi-strategy cochlear implant. It still has basically the same look, but it's a little bit different in size. Another difference is that there are only eight electrodes as compared to 22 electrodes. It's basically 16 areas of stimulation though because it's eight electrode pairs.

Figure Five and Six are photographs of the exterior part of the Clarion and the Nucleus 22, respectively. The difference is that the external part of the Clarion is basically two parts. In contrast, the external part of the Nucleus 22 consists of three parts. The Clarion has the microphone and the magnet combined in one round part, whereas the Nucleus 22 has two separate parts - a magnet and a microphone.

The Clarion has three user selectable speech programs, whereas the Nucleus 22 does not allow that. These are selectable by the user at any time. I'm not going to go into all the details about the different programs because that is something that an audiologist can explain better. But certainly if you have questions regarding the user selectable programs, you can talk to the company representatives later.

Now, you may notice the name Spectra 22. This is the newest version of the Nucleus 22 processor. This model, which has been out about two years, is improved over the previous model, especially in the area of noise reduction. People range in ability to use the implant from zero to maybe ninety-eight percent accurate understanding of speech. This clearly
indicates that a cochlear implant is not necessarily going to help every single person, because there are some who do not benefit that much. It's a fact. I've asked my surgeon, can he predict who will benefit and who won't? He has said that there is absolutely no way of knowing. It's a chance that you take. I took the chance because I had nothing to lose, only something to possibly gain.

The Clarion model is labeled a multi-strategy implant. Basically this recognizes that all persons are not the same due to the condition of their auditory nervous system, their cognitive abilities, and various listening tasks that are needed. The Nucleus 22 also basically provides multi-strategies as well. There is one difference between the two models. With the Clarion, there are two strategies that the audiologist can choose depending on what seems to help you the most. The two different strategies are either using continuous electrical signals which are simultaneously sent to all eight channels or the CIS strategy, continuous independent signals, where all the channels are not stimulated simultaneously. Processing strategies are still evolving and there are limited pre-implant diagnostics that can be performed. These differences are a little bit too technical for much discussion here, but it gives you an idea that there are some additional features on the Clarion that may or may not help you. And I would advise you to investigate both implant devices as well as all other options.

In order to be considered a candidate, Nucleus 22 uses the following criteria:

- Profound bilateral sensorineural hearing loss;
- Little or no benefit from hearing aids;
- Language acquired before hearing loss became profound;
- No medical contraindications;
- High motivation and appropriate expectations; and
- Support from family and friends.

These criteria are the same for the Clarion. These criteria include the idea that a person would derive little or no benefit from hearing aids. But what has changed this past summer is that the FDA approved implantation in persons with a sensorineural hearing loss (nerve
deafness) who understand speech with less than thirty percent accuracy. This is a big change! Before it was only for people who had profound hearing loss in both ears. Now people with severe to profound hearing loss are candidates. You should remember that to become a candidate people are tested with random open set sentences, with hearing aids on, and without any visual clues. So if they benefit from hearing aids, and can accurately understand more than thirty percent of what they hear, then they are not a candidate. Other criteria of candidacy include that there must be no contraindications to surgery and the person must have a desire to be part of the hearing world.

One question that I am asked quite often is "Why only one implant? Why not two?" So I asked my audiologist and she said that they have tried two implants in Australia on four different people and they have not benefitted with binaural reception of sound. Hearing aids can give you binaural reception. That means that hearing aids can sometimes tell you the direction in which a sound is coming from if you have two hearing aids, but this doesn't work with two cochlear implants. So you only need one.

Another question that comes up quite frequently concerns magnetic resonance imaging (MRI). People ask, "Can you have an MRI with a cochlear implant?" As of now, the answer is generally "no." However, the Nucleus 22 now has developed a special design that allows a person who uses it to have an MRI. The internal part does not have a magnet in it, and it connects to the external part by means of a "patch" about the size of a dime. The patch has a magnet in it, and must be placed on a shaved area directly over the internal part. It's much like putting on a band-aid that you connect the exterior part. The patch must be changed every two or three days, but it enables individuals to have MRI scans who might need them. Clarion is in the process of developing an implant with this same capability. It's generally good for consumers to have competition among different manufacturers of any product. We're going to see a lot of improvements in cochlear implants and hopefully fast.
Another frequent question is "About how much does an implant cost?" Well, that's an interesting topic. I have heard people say that their insurance won't cover the cost of two hearing aids, but it will cover the cost of an implant. Hearing aids may cost $2,000 apiece, but most insurance will cover implants at a cost of $30,000 to $40,000. So there's something wrong with our health system.

What about rehabilitation? Well, it's a necessity for children who are implanted prelingually or at any time in order to learn speech. There needs to be a lot of training to actually listening to sounds and connecting them to what the sounds actually are. If you are a post-lingually deafened adult, your brain remembers what the sounds really are and connects them with the sounds that you hear with the implant. But, in some cases adults do need rehabilitation in order to improve their speech. I know that Cochlear Implant Club International (CICI) also has a lot of information on this including both videotapes and audiotapes.

I think there should be more emphasis on providing some counseling for individuals both before and after implantation. I understand that they do provide it in some programs. I have been trying to encourage that at Johns Hopkins. For some people implantation entails a very difficult adjustment; for others, it's just a very natural adjustment.

How do we determine the success of an implant, and how do you choose which device is for you? Well, these are questions that I get a lot, so I asked my surgeon, Dr. John Niparko at Johns Hopkins Hospital, and he said "Nobody really knows which is better at this time. There are no investigational studies that are controlled in the way that we need them to be in order to clearly understand which device is better for which individual. The bottom line is that there's substantial overlap in scores on auditory tasks between the two devices." I personally believe that it is the computer upstairs (your brain) and not the one on your belt that determines the performance.
Question from the floor: What are your recurring costs for batteries, new cables, replacements of a unit, and so forth? What are the differences in the repair and maintenance costs of the Nucleus 22 and the Clarion?

Carol Sliney: Regarding the difference in cost between the replacement parts for the Nucleus 22 and the Clarion, the representatives from the two companies are saying that the costs are about the same for replacement parts. When I recently decided to upgrade my processor to the new Spectra 22 that cost me three thousand dollars. Many insurance companies will cover the upgrade costs but mine did not. So it can be expensive if you're talking about replacing the whole processor, but the costs for cords and batteries is relatively minimal.

Question from the floor: Can you replace the processor on all of the implants, or will there come a time when you will have to have a new implant? Are they always compatible all of the time?

Carol Sliney: Up to this point they have been compatible in that you only need to replace the processor. It's the external part you're replacing. The internal part stays the same. They have also removed the internal part for people who have had difficulty. That's been a very, very small percentage, but they can replace the implant itself if necessary.

Question from the floor: What's in the future? I mean with regard to research and development; what are the trends?

Carol Sliney: They are talking about combining all of the external parts into one miniaturized piece that will fit on the head thus eliminating the cord. They don't know how far into the future that development might be.
From the floor: Another trend is towards better speech coding strategies, and I think that's the bulk of the work that's going on now.

From the floor: I see a lot of people sitting in this room who have damage to the acoustic nerve rather than the cochlea, for example, people with neurofibromatosis-type 2 (NF-2). I haven't heard anything about the brainstem implants. Do you have any information which you want to share?

Carol Sliney: Yes, I am aware of the development of the brainstem implant. Would either of the cochlear implant company representatives like to explain something about that device.

Cochlear Corporation representative: The auditory brainstem implant is an investigational implant that is basically the Nucleus 22 cochlear implant, but with a different electrode array. It uses only eight channels or contact sites. You saw earlier that the cochlear implant is a long thin wire-type device, but the brainstem implant is almost like a flat plate. The brainstem implant is designed for people who have damage to the auditory nerve, and it is implanted directly into the brain stem. It's a very delicate procedure.

The brainstem implant research is being very closely monitored by the FDA. It's almost comical the number of tests that they have the audiologists running on the brainstem implant subjects. Currently there is a meeting down in New Orleans of the brainstem implant investigators. Thirty-two brainstem implants have been done, with four of those patients having NF-2. Up to this point 26 patients have been stimulated. The implant has not worked for three patients, and that's for a variety of reasons.

We received our clinical investigation go ahead on the basis that the implant might help to improve speech reading. Some of the results that we have seen are that there are several people of the 32 who are now getting open set discrimination. Those getting excellent enhanced speech reading capabilities are scoring in the 80 to 90 percent range, which is absolutely remarkable.
Most brainstem implant procedures have been done out of the House Ear Institute in Los Angeles. One of the most exciting things that has happened in this program was when one of the audiologists received a phone call from one of the implant patients. Granted, it's only one person out of 32, but it is just remarkable that she's actually using the phone. It's a very preliminary investigation, and it will probably be at least two years before we see any movement with the FDA to make the brainstem implant more widely available.

I think it is very important that we understand the distinction between the cochlear implant and the brainstem implant, and realize that if a person has nerve damage they should not seek a regular cochlear implant.

**Question from the floor:** Just for clarification, are you saying that the FDA has not yet approved the brainstem implant except for research?

**Cochlear Corporation representative:** That is correct. The brainstem implant is still an investigational device, and as such is usually not covered by insurance. The protocol was set up so that the implant is only done at the time of a tumor removal because of the critical nature of where the implant is placed. We would not expect anyone to have that type of surgery simply for implant purposes. The side benefit is that the insurance companies pay to have the tumor removed, which is a big chunk of the cost of the surgery. But in most cases they will not pay for the implant itself. However, several sites have grants that are eliminating a lot of those costs for the patient.

**Carol Sliney:** Thank you very much, and now let's move on to our panelists. I will call upon each one individually. We have Terri Lambert, Diane Tokarz, and Jay Mabry with us.

**Terri Lambert:** Good morning. My name is Terri Lambert and I'm president of the Illinois Cochlear Implant Club and treasurer of Cochlear Implant Club International. After working for 33 years in the accounting department of a large automobile financing company, I retired
in September of 1988. My hearing problem was a progressive nerve loss that started in my late teens and in 1988 I was considered profoundly deaf. I could not wear any type of hearing aid and get any benefit from it, so for the next four years I pretended I was a hearing person. Many people were aware of my hearing problem, but given the fact that I had such good lip reading skills, they did not know how severe the problem was.

Shortly after retirement, I went to visit an ear specialist because of an ear infection. While I was there, I decided to check on hearing aids. I figured that with all of this new technology, they should have some hearing aid that would give me some help. I figured that if they could send a man to the moon, they should be able to invent a hearing aid that would allow me to hear.

I was told that since I was profoundly deaf my only hope was not a hearing aid but a cochlear implant. I was given the name of Dr. Richard Wiet in Hinsdale and after being tested it was decided that I was indeed a candidate. I didn't waste any time. I had the surgery right away, so I was implanted with a Nucleus 22 in July of 1989.

From my perspective, it was the best decision I had made in my whole life. I can hear, understand speech, and listen to sounds that I haven't heard in many, many years. I hear the doorbell, the telephone, the birds in the trees, and the microwave. I can hear when I leave the lights on in the car and the buzzer goes off, or if I leave the keys dangling in the ignition. It has changed my whole life. It's wonderful.

It's also given me more self confidence. Now, when someone is talking to me and I don't understand everything that they say, I just say -- and I'm not embarrassed to say, "I'm sorry, I'm deaf. I didn't understand everything you said. Would you mind repeating it." And I'm also not afraid to get up in front of a group of people and be scared that someone is going to ask me a question and I won't be able to hear what they are saying. So the cochlear implant
has changed my life. It's been a change of life for my whole family. Everybody relaxes now.

Before the implant, I didn't know any other deaf or hearing impaired person, and I didn't know any organization that provided support to hearing impaired people. So, while I was sitting in the doctor's office waiting for my appointment with the audiologist, I saw a copy of Contact (that's the CICI journal), and I also saw a copy of the SHHH Journal. After reading several copies of both journals, I decided that they contained a lot of information that I could use. So I joined both organizations.

After joining a local SHHH group, I heard about ALDA, so I also joined ALDA. I met a lot of wonderful people and made a lot of new friends in these organizations, a lot who have cochlear implants, but I felt there was something lacking for people with cochlear implants. So in May of 1990, with the help and encouragement of my audiologist, I started a support group for people with cochlear implants. It's called the Illinois Cochlear Implant Club.

We meet four times a year at the College of Dupage in Glen Ellen. We have meetings where we have sharing of experiences and problems, and also we have guest speakers who talk about subjects that are important to people with cochlear implants. We encourage anybody who has a cochlear implant, or is thinking of having a cochlear implant, or is simply wanting more information about cochlear implants to attend our meetings.

We also put out a bi-monthly newsletter that has all the highlights of all the meetings as well as any information that I find that I think will be interesting to people with cochlear implants. Many of the people in our organization live far away, since we cover the whole state of Illinois. So a lot of them can't make the meetings, but they do enjoy reading the newsletter.

ICIC is a chapter of CICI, which is the only national organization that is wholly devoted to implant related issues. CICI was started in 1981 by a few people who had cochlear implants
in order to give mutual support in learning how to live with a hearing impairment. CICI has expanded its scope to where it now advocates for better insurance reimbursement for cochlear implants and enhanced community awareness of cochlear implants. They are advocating for cochlear implants in children. They put out a position paper responding to the NAD stand against implants in children.

CICI also puts out a newsletter and a quarterly journal called **Contact**, which is full of information about cochlear implants written by people with cochlear implants or their support person or parent. They have a lot of information about cochlear implants in children.

CICI also has biennial conventions similar to ALDAcon, at which they have panels, workshops, and presentations by audiologists, psychologists, doctors, and so forth -- anything that would be important to people with cochlear implants. The convention this year was in Irving, Texas over Memorial Day weekend. In 1997 it will be in Sturbridge, Massachusetts in late June. Sturbridge is about fifty-five miles from Boston, and is a very, very picturesque town. Thank you.

**Question from the floor:** How active are you in outdoor activities or strenuous indoor activities?

**Terri Lambert:** I belong to a health club, and I do aerobics three days a week. I bicycle and I walk. I'm very active.

**Comment From the floor:** My concern is if you're an active person you're going to wear out these parts and you're going to have a lot of maintenance costs.

**Terri Lambert:** No. The parts don't wear out. The only thing you have to think about replacing is the cord. They get stiff and have to be changed. Now, the processor is different. This is the third processor I have had. The first one I had for three or four months, and they
came out with the next one which I had for about five years. Then next they came out with the new one, the Spectra. Each one has been an improvement. But I don't wear the parts out.

**Carol Sliney:** I haven't heard of anyone having problems with the parts wearing out either. I do know that we have to be a little careful about sweat and moisture, but it is nothing like the problems that moisture created for hearing aids.

**Question from the floor:** Do you wear your implant when you're working out?

**Terri Lambert:** I wear it all the time. The only time I don't wear it is when I go to bed. I take it off at night and that's when my husband wants to do his talking. In the beginning I would ask if he had anything else to say before I took off my things. He would say "no," and about fifteen minutes later he would come in and want to have a big conversation. But otherwise I only take it off at night and I put it on in the morning.

**Comment From the floor:** I would like to clarify a little more what Terri is talking about. I have had my cochlear implant since 1983, and I am very active in boating, fishing and everything. Of course I take the processor off if I go swimming, but the internal parts are okay. You don't ever have to worry about that.

**Question from the floor:** How do you identify yourself? Are you hard of hearing or deaf?

**Carol Sliney:** People often ask me "Are you hard of hearing or deaf," or sometimes they will add "hearing." For example, in the Deaf community it's very important that you be able to identify yourself. When asked that question, I say that I'm both deaf and hard of hearing, because with the implant, I'm hard of hearing. Without it, I hear absolutely nothing, so I'm deaf.
I wanted to be sure that I had a good balance on this panel, and it was difficult to find someone who was not satisfied with their implant. However, I did find someone who previously was not happy with her implant. She experienced a very unhappy beginning with her implant and she will explain that to you. I think it is important that we know about this, as it can happen to anyone. We welcome Diane Tokarz.

Diane Tokarz: Good morning. My name is Diane Tokarz and I'm from Chicago. I work for the Federal Aviation Administration. I received my cochlear implant in Chicago at Mercy Hospital in December of 1990 -- almost five years ago now. I really wanted the CI for myself because I was so frustrated, depressed, and simply tired of not being able to hear. I did my homework for three years studying about the implant, the positive and negative features. However, I never really remember reading anything about things that could possibly go wrong. Besides, at that point in my life I figured that I had nothing to lose. I needed something, no matter what.

So I went into the hospital, had the surgery, and woke up with a lot of pain. I stayed in the hospital for five days, whereas usually this is an overnight procedure. You are in and you are out the next day. But, of course, nobody knows if there's going to be complications with any type of surgery. I knew this, and I had of course signed a surgical release.

While I was in the hospital it was very important for me to have interpreters in order to know what was going on around me. However, for most of the time I had no interpreter support. I couldn't comprehend what was going on so I was very frustrated. I thought this should be a part of the program; if you're deaf you need to know all of what is going on.

While in the hospital I developed a massive infection. I was in constant pain, and I was so doped up that I didn't know who I was or what I was doing. At the end of five days I begged them to let me go home to feel more comfortable. So with more medication I was sent home with this infection.
I was in constant pain. I would just sit, and I could not move my head. I remember on Christmas day I had my husband call the doctor because I just couldn't take it anymore. So the next day I went in and my neck was puffed way out. I couldn't touch any part of it because of the pain.

My doctor was out of town, so I had his assistant look at the infected area. Again, I had no idea of what they were going to do with me, and he proceeded to lance this infection without me knowing it. When he cut it open I thought I was going to go through the roof. So I was sent home again and tried to recover.

Then when I had my hook-up, they asked "Aren't you happy?" and I'm sitting there with this look on my face. I just wanted them to get it over with. They proceeded with the mapping of the processor, and of course it all sounded like Mickey Mouse to me. I knew this would happen from talking with other implant recipients. So I went home and I couldn't understand anything.

They have you go back almost immediately and have a follow-up change in the mapping. Then they had to map me all over again, continuously, and it was still all this racket. This went on for months and months. I had over 75 maps within three or four months with them constantly trying to convince me that I was picking up something. I kept saying "I can't understand." There was no speech discrimination at all. So they more or less said, "Sorry, we simply don't know what to do for you."

So I called the people at the Cochlear Corporation in Chicago, and told them my story. They were shocked and said, "Wow, we really have no other people that have had your problems." So my next step was, of course, to change doctors. But I waited for awhile. I really was beginning to think that it was all in my mind, that my brain simply was not picking up speech, and that I was slow. I know with some people that happens.
So I waited, and during that time I would keep my hearing aid on to help with the CI. When I went back to the doctor he said "You must take that off. You need to really concentrate on your CI." And I said "I can't. I need to hear something or have a feel for sound around me." And they said "No, it's better if you depend completely on the CI."

But I knew myself. I didn't care what works best. I needed something, so I continued to wear both devices. In time I became less aware of the hearing aid and tried to switch over, but it was a very slow process. After two years time nothing was working for me. It had taken me eight years to accept myself and get ready to have the implant, and then in two years I just crashed. It was just nothing.

I changed doctors and I went back for more tests. I still had zero speech discrimination. Nothing was working for me. So I just stopped concentrating on trying to hear and understand because it was not helping me. After three years without consciously trying to understand with the aid of the implant, I just forgot about it. I always wore it, but I was not so stressed out. I simply had to accept it, and with the passage of time, slowly I noticed an improvement.

I could never use the phone, and I still can't. Because I work with the same people every day, I was not sure if I was speechreading or if it was the signing that was allowing me to understand. Or was the implant really working? It was very confusing, and I was not sure what was working. And then I realized that when I took the CI off I could hear nothing. I was aware of no sounds. But when I put it back on I knew something was better, something was working.

This was really a traumatic experience for me, but I can't live without the implant now. It's wonderful. I wouldn't give it up now for a million dollars. It's wonderful! But I am still way behind most implant recipients. There is still no good speech discrimination.
I forgot to mention that I have a Nucleus 22, and one year ago I upgraded to the new Spectra processor because they thought it would help me get better speech discrimination. I only had two days in which to decide if the Spectra was providing any addition benefit, which was certainly not long enough for a fair assessment. But I decided to keep it, and I honestly don't feel that there has been any improvement with that change. Maybe in time, like everything else, it will change. I can't say. But my attitude regarding the implant is very positive now.

I served on the national CICI board when I first got my implant because I wanted to make sure that I learned everything I could about the CI. My advice to you is to get the best doctor and the best hospital that you can. Do your homework, and learn everything that you can about the implant, both pro and con. That's very important. But, always remember that exactly how the implant will work will be different for every person.

**Question from the floor:** How would I know if my doctor is not a good doctor?

**Diane Tokarz:** You check him out. You can call the offices of the Cochlear Corporation in Colorado if you want to ask about your doctor. They have a list of doctors who do this surgery, including the percentage of successful implants for each doctor. Generally you don't have "bad" doctors out there doing cranial surgery.

**Carol Sliney:** This is a very specialized surgery, but you definitely want to check out the doctor before having any surgery. And I do agree, I would check with the Cochlear Corporation and Advanced Bionics, the manufacturers of the Clarion.

**Question from the floor:** I know that, but the problem is that Diane's doctor was recommended to her but turned out to be a bad doctor. Right?
Diane Tokarz: No. I chose my doctor. If my situation had been different, I would have left Chicago for the surgery. But because I was working, I didn't want to take the time to travel. I had great confidence in my doctor. He was very supportive of ALDA, and I felt like I knew him personally. It was only after three years that I decided that I should have gone somewhere else.

Advanced Bionics representative: I think that I speak for both Gary at Cochlear Corporation and myself when I say that as the manufacturers we really can't make recommendations concerning who is a good surgeon. However, we can say who is trained in the surgery.

I'm an audiologist from a clinic and have worked with a cochlear implant surgeon. My opinion is that you go to a surgeon who listens to you. Would you want to work with a surgeon who only talks to your spouse or your mom and always asks them about your hearing? Do they listen to you? Do they tell you the pros and the cons? If they tell you it's a miracle cure, you know something is wrong.

Carol Sliney: I would add that talking to other people who have a cochlear implant about doctors, hospitals, and audiologists can often give you a lot of information. My experience at Johns Hopkins Hospital in Baltimore was terrific, from the moment I entered until the moment I left. It was the best service I have ever had for any surgery. They were very sensitive to my needs.

Comment from the floor: Today the doctors are much better trained than in the past, and the technology is much improved. I remember when I got my first implant in 1983. I had the 3M implant and was only in the hospital for two days. I was the first patient in the state of Florida to have an implant, and I was my doctor's first implant patient. In other words, we were both new. But he had trained in California under Dr. House, who is one of the real pioneers in the development of the cochlear implant. I had called California on the TTY and
spoken to some of the patients of Dr. House. I talked to one patient who was one of the early pioneers with whom they had experimented. They had put electrodes in her neck, and she looked like Frankenstein. But she assured me that this was one of the greatest things that had ever happened to her, so I went ahead and had that implant. Everything was fine; there were no complications at all.

Then I had a Nucleus 22 implant on the other side in 1987. I still have both my 3M and my Nucleus 22 implants. I don't use the 3M anymore, but I could if I wanted.

So don't be afraid. The implant is good. After my last operation I went back to work the next day. The operation is really, as I understand it, quite simple. The bone operation is like a mastoid operation, and the rest is microsurgery where they insert the implant in the cochlea.

**Carol Sliney:** I have one friend who had his surgery at Johns Hopkins and they do it as out-patient surgery now. He went in for surgery at 8:00 am, and he was out by 12:30. He said he felt like he had just gone to the dentist to have a tooth pulled. It was a very minor procedure. He didn't have any problems, but each person is different.

**Question from the floor:** How long did you have to stay in the Johns Hopkins area for the training process?

**Carol Sliney:** I live in Baltimore, so it was not a problem for me. I do have one friend who came all the way from Texas to have the surgery. She had talked previously with the surgeon, and then came once for testing and once for the surgery. After the surgery she stayed around for three days to make sure that everything was all right. Then she went home. About a month later she came back for a period of three days for hook-up and mapping of the processor. That's the last time a patient has to go there unless there's complications. The
rest of the time the mapping changes can be done anyplace where there is the proper computer equipment and a trained audiologist.

Our next speaker is Jay Mabry, and he has the Clarion implant.

Jay Mabry: Hi. My home town is Decatur, Illinois, and I'm a part-time student and part-time roofer. My hearing loss started when I was 25 years old, and I have been hard of hearing for ten years, profoundly deaf for five years, and deaf as a door knob for a little over a year.

I graduated from Eastern Illinois University in 1970 with a degree in marketing and soon after got into the restaurant business. I ran a fairly large restaurant for 23 years. I had a staff of about 30 people and hundreds of customers every day.

For the last 27 years I have been involved in a lot of sports, such as water skiing and triathlon competition. Basically I was involved in anything that was competitive, and I always applied myself a hundred percent. I don't have a lot of talent, but I knew that if I always gave a hundred percent I could end up doing well -- and I did. I had real good success both in business and in my sports.

But my hearing started going bad. I couldn't hear my customers anymore, and that's bad in the restaurant business. I couldn't understand my staff unless I got them off in a quiet place. The last year or so of operation, it was really terrible with my being profoundly deaf. I wore two hearing aids, one in each ear, and neither one of them were turned on because they didn't do me any good. When I told people that I had a hearing problem, they didn't seem to understand. So I had to fake it a lot with my customers, and that was pretty stressful. Even more stressful was the fact that my business started to decline. I had to close the business at a time that I was profoundly deaf, and when I did that I put 30 people out of work -- and
some of them had worked for me for all of twenty years. I think the average time that a person had been on my staff was nine years, and I felt real sad about that, but I was in kind of a desperate situation.

I stayed home a lot after I closed the restaurant, and I just didn't know what to do. I was depressed. I joined a SHHH group and they helped, but I became kind of a hermit. I stayed at home, lost touch with my friends, and lost touch with my family. I couldn't understand what was happening. I wanted to talk to my kids and I wanted to talk to my wife, but it just didn't work out too well for me. I took some signing classes, which are great if all the people around you sign, but I didn't take to that too well.

I finally got to the point with my depression that I went to my case worker at Illinois Department of Rehabilitation Services and said, "I'm fed up with my life. I don't know what I'm going to do, but I've got to do something." Actually, it didn't start out like that. She just asked the right questions, and pushed the right buttons, and that's the way it ended up. So she said, "Let's investigate a cochlear implant for you," and I said "great." Then I wondered if I really wanted to be a bionic person, but I didn't care. I needed to get back into society.

We investigated the cochlear implant, and I also did some investigating on my own. I found out about the Clarion research project at the University of Iowa. I did some calling and became part of their investigational project. My implant was done by Dr. Gants. I've had it for a little over a year now, and I have been pretty happy with it.

I'm a full-time student now, and my life has changed quite a bit. I think what I'm really here to say is what my implant has meant to me. I have looked for the right words for the last two or three weeks, but I simply can't find the right words to tell you what this implant has meant to me. I lost my confidence, and now I have it back. I had lost hope, and now I've got it back. I dropped out, and now I'm dropping back in. I think it is a gift from God, and a gift of modern technology, and it's a personal miracle for me. And that's about all I can say.
Comment from the floor: I'm not a cochlear implant recipient, but I have two important comments I want to make about surgery. First, one way to check out a surgeon is to contact your state medical association. If you can't find the number in the phone book, call directory assistance through the relay. If the person at the medical association cannot answer your questions, they will either get the answers for you or tell you how to obtain them. Find out if your surgeon is board certified. That will tell you his skill level. And you can also find out if he's done that kind of surgery before and for how many years.

My second comment concerns complications like pain. Last summer I had surgery for a very minor hernia. When I woke up after 90 minutes in the operating room I was in a lot of pain, and I couldn't make it through the day without codeine for at least a week. My general surgeon was very experienced, and has been doing hernia surgery for many years. I believe the problem was my body. I simply had a low threshold of pain. It was not the surgeon's fault. It was just the way my body responded to being assaulted and invaded with a knife. That you can't predict. If your body is that way, the best surgeon in the world can't do anything about it. That's the risk we take when we go for elective surgery.

Question from the floor: You have touched lightly during the workshop on the advantages of surgery. Can you talk a little bit more about the learning curve for improving the benefits of a cochlear implant during rehabilitation after the surgery.

Carol Sliney: I don't have the research results here concerning that question. And I'm wondering if any of the other panelists have had experience with rehabilitation. Jay, did you have any rehabilitation?

Jay Mabry: Given that I was on an investigative panel, I had to try a different processor map every three months, whether I liked it or not. Well, if I really hated it they would change it, but otherwise I had to have a different map every three months. Each one got progressively better as I found what I liked. Rehabilitation is really a joy because it consists
of nothing more than listening for sounds that you haven't heard. My audiologist told me that the learning curve stops after about a year.

**Carol Sliney:** I was told it stops after about two years.

**Jay Mabry:** The learning slows down with the passage of time. I tried to prevent that by really paying attention and concentrating through the whole process. That's all you have to do is pay attention to what you hear. That's the extent of the rehabilitation. I agree with Carol when she said that the biggest rehabilitation has to take place up here in your head.

**Carol Sliney:** You need to keep a positive attitude, and not start thinking, "Oh, darn it, I can't hear that sound. What's wrong with me?" You shouldn't think that way. Instead, you need to say, "Wow, I'm hearing some things that I didn't hear before."

Using my new Spectra, which I have had for four months, I can go into a bar with a group of people, and I can pick out the sound of each instrument that is playing in the band. Even if there's a crowd of people standing there and everyone's talking I can still hear the music. I'm just shocked to think that I can do this, because I certainly couldn't before I got my implant. I couldn't even be near music before, even when I turned off my hearing aids, because sound was so painful. I had a very severe recruitment problem, which is when you can hear sound but have pain at the same time. That was a part of the reason that I had decided to get my implant in the first place. My doctor had pretty well guaranteed me that the recruitment problem would be helped.

**Comment from the floor:** I also have a cochlear implant. I was hooked up on July 8th of last year. For my rehabilitation, I got a walkman radio and borrowed "talking tapes" from the library (those are audio tapes which contain the text of books). I listened to talking tapes to help me learn to understand words much better. That was the nature of my rehabilitation.
Carol Sliney: I did not talk about other technological devices and ways to hook them up to the implant. I generally share that information among people with cochlear implants, but the specifics of that information might not be very useful for most of you at this time. However, I will mention a couple of things in general.

I use an FM system extremely well when it is connected to my implant. It is very valuable in large meeting rooms if I have to be far away from the speaker. And depending on the acoustics of the room, it just attaches directly to the implant with a special cord. No other sounds are picked up, only what comes through the FM system. I also use a loop system for meetings, and that requires another pickup device. Some people use an exterior microphone for one-on-one conversations. I'm doing so extremely well in noisy environments that it's mind boggling.

Question from the floor: This may sound like a stupid question, but does the distance that you can actually hear sound vary among people with cochlear implants?

Carol Sliney: That's a good question. I can hear the people speaking way back over there at the end of this room, and that's quite a distance. There is no way that a hearing aid could pick up sounds from that far away. However, while sounds from the back of the room may be clear enough for me, they will not necessarily be clear enough for Jay. We each vary, and the effective distance of the implant is not the same for all of us.

Jay Mabry: Speech perception is not too good for me in a group situation when the speaker is relatively far away. But in one-on-one situations, when the speaker is close, I hear and understand a hundred percent of what is said.

Carol Sliney: There is one more important thing that I should mention. I have noticed that all of the panelists here today have very clear speech. And people who have known me for a long time have noticed that my speech projection and pronunciation have really improved
since I got my implant. So I think that improvement in the quality of one's speech often is a
definite benefit from the cochlear implant. It's time for lunch, so I think we had better close.
Thank you all for coming.
The microphone receives sound and transmits it to the speech processor, which selects and codes the information useful for understanding speech.

The transmitter sends the coded signals across the skin to the internal receiver/stimulator, which converts the codes to electrical signals.

The 22 electrodes in the cochlea stimulate the auditory (hearing) nerve. The brain interprets these signals as sound.
Figure Three - Internal Components of the Nucleus 22

- 22 Channel electrode array
- Receiver/stimulator

Figure Four - Clarion Implantable Cochlear Stimulator (ICS)

- Hermetic ceramic package
- Bi-directional telemetry
- Capacitively - coupled outputs
- 8 independent parallel output circuits
Figure Five - Exterior of the Clarion Speech Processor (SP)

- Three selectable speech processing programs
- Programmable microprocessor
- Metal case
- Integrated headpiece

Figure Six - Exterior of the Nucleus 22

Headset
- microphone
- transmitting coil

Speech processor