The Challenge of Tomorrow

Selected Proceedings of ALDAcon '97

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TABLE OF CONTENTS

ALDA PRESIDENT'S FORWARD ......................................................... v

ALDA EDITOR'S COMMENTS ........................................................ vi

RT-31 EDITOR'S NOTES AND ACKNOWLEDGMENTS ......................... vii

AUTHORS/PRESENTERS ............................................................... viii

ADJUSTING TO DEAFNESS .......................................................... 1
Mary Clark and Steve Larew

CREATIVE WRITING TO COPE WITH HEARING LOSS AND OTHER
LIFE ISSUES ........................................................................... 13
Mark Dessert

OH, THAT'S SICK ........................................................................ 17
Shawn Lovley

TREATMENT OPTIONS FOR NF2 - FROM THE PATIENT'S POINT OF VIEW .... 21
Frank Fuscia

SURVIVING FAMILY GATHERINGS ............................................. 27
Cheryl Heppner and Fred Heppner

DEAFNESS IN THE CHURCH ....................................................... 35
Rev. Jan Gronborg Eriksen

JOURNEY THROUGH LATE DEAFNESS ...................................... 43
T. Jordon Goulder

MENTAL HEALTH SERVICES FOR ADULTS WHO ARE HARD OF HEARING
OR LATE-DEAFENED ................................................................. 55
Carren Stika

CHALLENGES TO ENHANCING REHABILITATION AND EMPLOYMENT
OUTCOMES FOR ADULTS WHO ARE LATE DEAFENED ................. 65
Douglas Watson, Steven Boone, Mary Clark, Keith Muller,
Cecil Bradley, and George Kosovich

CART (COMPUTER-ASSISTED REALTIME TRANSLATION) TECHNOLOGY
FOR TODAY AND TOMORROW .................................................. 81
Heywood "Woody" Waga and Marylyn Howe

iii
THE WORLD WIDE WEB AND RESOURCES RELATED TO HEARING LOSS . . . 91
Roy E. Miller and Ken Arcia

HOT NEW TECHNOLOGY .................................................. 101
Judith Harkins, Jerry Aldrich, Gary Moulton, and Mike Hoghooghi

HEARING TECHNOLOGY RESEARCH AND ACCESSIBILITY:
DISCUSSION AND DIALOGUE ........................................ 115
Matthew H. Bakke and Anita B. Haravon
ALDA PRESIDENT’S FORWARD

Many of those attending ALDAcon 97 in North Miami Beach, Florida, commented that it offered some of the best workshops they’d ever attended. We are delighted to bring you these proceedings so that you, too, can also experience the pleasure of learning from both peers and professionals.

Enjoy!

Cheryl Heppner, ALDA President 1997
ALDA EDITOR’S COMMENTS

Attending one's first ALDAcon can be an overwhelming experience. The sheer wealth of opportunity to learn and grow is amazing. 1997 was my first con, and I vividly remember sitting down on arrival and looking over the program book, wondering how on earth I was going to be able to do everything that I wanted to do.

As it turned out, I couldn't go to more than a fraction of what was offered; the workshops are presented in groups, and there are so many of them. The old saying "so much to do, so little time" leaps to my mind now as I look back; and often during those few days, I found myself wishing that I could be in about five places at once.

I am fairly young in ALDA years, and had no idea at the time of the '97 CON that ALDA puts together each year a selection of the workshops for publication for precisely those reasons. But when Cheryl Heppner, our president in 1997, asked me to help edit the proceedings I signed on -- and my education began. Working on the papers, I quickly realized how important they are; for here was a way that I COULD be in five places at once, even if I was unable to attend the CON in person. I hope that the information presented here will prove to be as interesting to others as it has been to me.

I would like to thank all those presenters who worked so hard, with so little warning time, to get this material into written form. To them we all owe a very large debt. Also, my thanks go to Douglas Watson and the University of Arkansas who assisted me in both editing and publication chores. Last, but not least, I would like to extend thanks to Steve Larew and David Coco who guided me through the whole process.

Carolyn Piper
The University of Arkansas Rehabilitation Research and Training Center for Persons who are Deaf or Hard of Hearing (RT-31) is pleased to have assisted ALDA in preparing and publishing *The Challenge of Tomorrow*. This book focuses on material presented at ALDAcon ‘97, 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.

In dedicating this publication to late-deafened adults, it is our hope that this document will serve as a printed record of the proceedings of this conference and become a resource to the field and those persons who were unable to attend the conference.

The conference convened October 15 -18, 1997 in Fort Lauderdale, Florida. This Ninth Annual “Meeting of the ALDAcon Clan” gave participants the opportunity to meet new family members, reminisce with the old, and gather the news that has occurred between the times. Special thanks go to 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 continues to provide a viable national forum for consumers and advocates who are interested in late-deafened adults.

Credit for this document belongs to the many individuals, organizations and programs that made the conference possible. Together with my ALDAN co-editor, Carolyn Piper, I would like to especially thank all of the presenters for the time and effort they devoted to the preparation of their manuscripts and willingness to work with us during the editing and publication process. We have tried to faithfully maintain the content and ideas of the individual authors. We readily accept responsibility for any deficiencies in the editing of the material and hope that our work has only served to clarify the ideas expressed by the authors. We would also like to sincerely thank the leadership and members of the ALDA board, both past and present, for their support for the completion of this manuscript.

I would also like to thank RT-31 faculty and staff -- Mary O'Rourke, Heidi Lefebure, John Schroedel, and Kathy Wheeler-Scruggs -- who provided assistance in preparing this document for publication and dissemination.

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ADJUSTING TO DEAFNESS

Mary Clark and Steve Larew

Steve Larew:

Mary and I are here to talk about adjusting to deafness, with the idea that sharing our experiences may help some of you who may be going through similar experiences. We will be talking about five different adjustment stages that occurred during our own personal experiences of losing our hearing. These five stages were identified by Frank Zieziula and Katherine Meadow from Gallaudet University. They conducted a study with about eleven deafened adults using personal interviews. With the information gained they were able to identify five stages of adjustment that commonly occurred when functional hearing is lost. The five stages are:

1. Spectrum of emotional responses
2. Secondary losses
3. Identity confusion
4. Acceptance
5. Need for competent professional assistance.

The reason that Mary and I do workshops such as this together is because we are different. We have had different experiences. It can help to hear different experiences from different people. I became deaf at the age of eighteen due to a generalized infection and fever. Actually, I am not really sure of the exact reason I became deaf. My deafness happened very suddenly. It happened in a matter of two weeks time. I was 18 years old. I was a freshman in college. I was going to classes. I felt sick as though I had a cold: a headache, earache, sore throat and cough -- the works! All of a sudden I noticed I couldn't hear the teachers in class. I could not hear the TV or the radio. The people in the dorm room next to me started telling me, "Why are you playing the radio so loudly in the morning?" Meanwhile, I am thinking: "It is not loud." I thought the radio was broken because I couldn't hear it, or that I could not hear as well due to the cold that I had. Two weeks later, the cold was gone, and I still couldn't hear.

I would go to class and not hear. I would watch TV and think the TV was broken. I would think my friends at college were mumbling. I didn't understand why this was happening to me.
I knew nothing about deafness. I had not met anyone that was deaf. I grew up on a farm in Iowa. I had met few people with disabilities. The only person I can remember meeting who couldn't hear was a 90-year-old woman -- when you are 90 years old, it is okay if you can't hear. That is acceptable. But I was only eighteen. Being deaf at eighteen is not acceptable. Eighteen year old people are supposed to be able to hear. You do not have problems when you are eighteen. That was my thinking.

I went through these emotional responses. Emotions? I was mad! Why am I becoming deaf? Why me? Why me? What is happening to me? What is wrong with me? I am deaf. I can't hear the radio. I can't watch TV. I can't use the telephone! I can't hear in class. I can't talk with my friends. What am I going to do?

I had become deaf. What do deaf people do? I did not know. I had no idea. I had no information about services for deaf people. I didn't know anything about sign language. I didn't know anything about assistive devices. There was not, at that time, a lot of technology for the deaf or hard of hearing.

All these emotions were inside me. I didn't know what I was going to do. I was really mad. I was trying not to admit that I was deaf. People can't see deafness or hearing loss, so it seemed to me that there was no reason for me to explain it. To be honest, I couldn't explain it. How do you explain to someone that you are deaf and can't hear? How many times have you gone out and had a person come up to you and speak to you, and your reply is, "I am deaf. I can't hear." What happens? People say "What?" and give you a strange look.

Now-a-days I have developed a standard answer when a person comes up to me and says something that I don't understand. The standard response is, "I don't know." I am not going to tell the person that I am deaf. Not the first time anyway. I say, "I don't know." Now, that can also be very embarrassing because I have no idea what I am saying "I don't know" to. A person comes up and asks me, "What time is it?" I say, "I don't know." They look at me. "Well, you are wearing a watch, you idiot. Why wear a watch if you can't tell the time?" That kind of thing is embarrassing, but it works for me.

I have been deaf for 27 years now. I have been working in the field of deafness. I tell myself that I have adjusted well to becoming deaf, but still when I go out in public, I am as bad as the recently deafened person because I don't explain to people that I am deaf. I hide it. I don't request special services or support.

Maybe most of you people in here are better than me because I don't ask for help. I just try to deal with it myself. My first perception of becoming deaf was denial. I thought that a hearing aid was going to solve my problems, because as a hearing person growing up, I had learned to believe the myth that hearing aids solve all
hearing problems. So I went and bought a hearing aid, and then went back to the dorm and tried talking with people. The hearing aid did not help me enough.

When I became deaf, I was looking for a cure. Something that would solve my problems. Really, I thought becoming deaf would be a temporary thing. I would work through it. I didn't want to stay deaf. I didn't want to live another seventy years or so as a deaf person. Negative things were happening to me. I couldn't listen to the radio. I couldn't understand TV. I couldn't talk with my friends. I couldn't use the telephone.

But the thing is, I kept hearing that word - can't, can't, can't! Can't! I was saying it inside myself. Can't! Can't! Can't! That was my thinking at the time when I became deaf. It took me two or three years before I found real information about things that I COULD do. That is a long time.

Now, three years thinking, can't, can't, can't is a long time. It should not have taken that long. It is not fair! We need information on positive things we can do when we lose our hearing.

As an individual, I can still do many things. Some things I don't do well, but there are still many things that I can do, even if I am doing them poorly. The only thing I really can't do is hear. It took me a long time to accept that.

But, I am lucky. I am lucky I was young when I became deaf. I had time to make the adjustment and go to graduate school. I studied rehabilitation counseling for the deaf. I consider myself lucky that I did that because in addition to learning how to do my job, I also learned that many deaf people have similar feelings, similar emotions about becoming deaf.

I want to talk a bit about my family. I look back and think I was very, very selfish. I was always thinking about myself. What was happening with my mom and dad when I became deaf? What was happening with my brothers when I became deaf? I didn't think about them. I didn't start to think about them until two years ago. For 25 years I was thinking about myself, my own experiences, and what I needed. My parents, my family, friends, what about them? What were they feeling at the time? This is an important thing to keep in mind as you go through the adjustment to deafness.

Mary Clark:

My experience is a little bit different than Steve's in the fact that I have a progressive loss. My hearing loss was discovered in high school in about 10th or 11th grade. I remember I had a very mild loss. So I went in for a hearing test, and they found out I had a hearing loss. At that time, probably my emotional response was much like what I also experienced for the next ten years as I eventually lost all my hearing. I
was very depressed. I cried a lot. I remember going home and crying, and thinking, "How could this happen to me?" I never really felt in denial, and I never really felt shock or anything, but I felt very depressed that this had happened to me.

My family's reaction was interesting because they basically felt that wearing hearing aids would fix the situation much like wearing glasses. Of course, now we know that is not true. It is, as we all know, kind of different.

Another thing was that I was not really permitted to feel bad about the situation. In my family the hearing loss was perceived as something that was not a big deal. It was, after all, just a "little bit" of a hearing loss. We all decided, at least outwardly, that it was nothing to get upset about.

That is basically how I grew up, until the time I became completely deaf. In college, I lost more hearing. I noticed a change. I couldn't understand people very well. I went back to the audiologist and found out that I had lost more hearing. I now had a moderate to severe loss.

I remember going to a professor who really had an impact on me in terms of helping me through this time. She was teaching in the deaf education program. I talked to her a long time. She said: "You know, Mary, it is okay to feel bad about this."

I was, for the first time, given permission to feel badly about it. I realize now with all the work that I do with late-deafened people, that this is a very important stage to go through. Everyone has to go through the grief process of feeling bad, feeling depressed, and then finally accepting the loss.

At that point though, I still really functioned as a hearing person or a hard of hearing person. I became "legally deaf" in college, but I didn't know sign language, and I did not use assistive devices. I got married to a hearing man. I didn't know anyone that had a hearing loss or was deaf.

Then I had children. After the second baby was born, my hearing dropped dramatically, and I became functionally deaf. I was also experiencing vertigo during this time -- between my late high school years and the time the second baby was born -- and none of my doctors could figure out why.

A lot of things changed for me during this time. There were a lot of family issues that had not been addressed before because of the hearing loss. Steve was talking about how the family members change as well. In my situation the same thing happened because everybody in my family knew me as a hearing person. Then all of a sudden I was deaf, and the interesting thing, too, is that when I lost the rest of my hearing I once more went through the stages of grief for a second time. I think that as people with a progressive loss experience more and more hearing loss, they go through those stages each time that they lose more hearing because their ability
to function changes. So that the need for adjustment is constant -- which is very difficult.

It was difficult for me. I was not always sure if it was the medication I was on for the dizziness, or if I was really depressed because of the hearing loss, but I became preoccupied with how people saw me. What I would do is look at other people for value. I would allow them to dictate my identity of who I was.

But my family was also experiencing these same emotional ups and downs that I was going through. So during the time that I was depressed, some of my family members were also depressed, or in denial. Some of them just couldn't accept what had happened to me. I still had some family members saying, "Well what is the big deal? What is the problem here? Just wear hearing aids and you will be fine." It had not impacted everyone yet that this was affecting my communication in a big way.

Like Steve, during this period I was busy thinking about myself. I did not realize how other people were feeling. Now, as I look back, I realize it was difficult for everybody involved.

It was not just the loss of communication, there were also secondary losses involved. My first daughter was three at the time that I lost my hearing. I still remember one incident very clearly where I was driving to day care to drop her off. She said something to me, and I didn't understand what she said. I just said "Yes," and then she started crying a little bit. She asked me again, and I realized I had given the wrong answer. So I said "no" the second time. And then she asked me again and I said "Let's wait. Let's wait until daddy gets home and we will ask daddy." I did not believe that was acceptable either. By the time we arrived at day care, I had this hysterical three year old in the car. All because I did not understand her. I had understood her before, but now I couldn't. We arrived at day care and I kept thinking, "What do I do in this situation?" She was so upset, I decided to ask another mother what my daughter was saying. For me, that is really when it hit me: "Boy, you really are deaf when you have to ask another mother what your own daughter is saying."

That incident to me was really the beginning of where I started to change. I realized that I had to feel better about myself -- for my kids if nothing else. Even now that incident is very painful for me to think about.

It taught me though that everyone, even small children, go through the grieving process. All of a sudden this three-year-old girl had a mom that didn't understand her anymore and needed help in dealing with that fact. I had failed to recognize her grief until that incident.
6 Adjustment to Deafness

Later, when I talked to my daughter about what was going on, she cried and cried. We talked about the future, and I told her that it would get better; that she would learn how to finger-spell and we would learn how to communicate better.

She is thirteen now, and she is just so great about communicating with me. But, I had to really go through the same process with all three children because it sort of hits them at some point or another that their mother is different than other mothers. That is not really a fun thing to have happen.

There were also other secondary losses. Many of them involved simple things which we could do before becoming deaf. When I first became hard of hearing, I could still talk on the phone, and did so all the time with much enjoyment. I loved to talk to people! Then all of a sudden I couldn't do this anymore, and that for me had terrific impact on my adjustment. Gradually I got to the point where the phone would ring, and I didn't want to answer it. Just hearing it ring would cause stress. It was a gradual process during an 18-month time period.

But it was also the beginning for me of a stage that I had to go through to finally accept the fact that I wasn't going to be able to use the phone like I had been able to before. Finally I sat down with my husband, and after a long talk, I admitted that I could not talk on the phone anymore.

Only then was I ready to try some kind of assistive technology. I went out and bought a TTY. I was still very, very isolated. I still knew no deaf people. I still relied a lot on family members for communication on the phone, and I wondered who I would be able to talk to even with a TTY.

But I did get a TTY. I also, through my job, finally met some hearing people that knew about sign language and deafness. That was a life saver for me too. Also during those months I joined ALDA -- which was at that time a self-help group that had just started in Chicago.

It took me a while to go to my first meeting. I was still a bit depressed and a little bit angry about what had happened to me. Also, still a little bit in denial. At first all I would say in the group was: "I am fine. I am doing well." But I kept thinking to myself: "Why am I here if I am doing so well?" I finally got to the point where I could really express myself and say how I really felt.

Another secondary loss that I had was loss of friendships. All my friends were hearing friends. I always tell people, when they ask me about losing friends, that you will find out who your real friends are when you become deaf, because those are the people that still stick with you. It's the people that leave, that probably never were really good friends to begin with.
After I became deafened, I didn't know any sign language. I usually relied a lot on lipreading but it got to the point where it wasn't working very well anymore. So that situation had to change in the family as well -- especially the family that I lived with for 24 hours a day. It became very difficult because I had always been a very good lip reader, and I finally just couldn't do it anymore. So I had to once more sit down with my husband and say: "You know, you are going to have to learn sign language because this is not working for me. I can't live with someone for 24 hours a day and not communicate with them."

So he did take a sign language class. That was an adjustment stage that he had to go through. I think that it hit Jeff at that time, too, that while he could fit into my world, I could no longer fit into his world communication-wise.

Still another secondary loss that I think of often, is social events. This is one area that I am still working on, especially with my husband. I prefer to hang around my deaf friends, or friends that can sign. Jeff prefers to hang around his friends. We have very few common friends that really understand the situation. It is hard to always make sure we both have what we want, and need, in any one situation. So in social situations, we discuss things ahead of time. If it is a business kind of thing for my husband we discuss that.

Honesty here is important. It has been helpful to say: "Okay, in this situation, can I rely on you for interpreting, or do you want me to leave you alone, and I will find something to do myself?" Sometimes I don't go if that is going to be the case. Jeff may make the same decision to not come if it is going to be a "deaf event."

We have some rules in our family for communication. At dinner time, for example, we all sign because that is what I understand the best. Another rule that we have is that the kids have to ask me first if they can go somewhere because for many years they would ask my husband first for permission because that was the easiest thing, and he would say: "Fine." Then he would forget to tell me, and I would be wondering where everybody was. So we made the rule that they have to come to me first. They have to learn how to communicate.

For a long time I would say, "Thank you," when my family used sign to talk to me. Then someone came up to me and they said: "Mary, why are you thanking them? The family has a responsibility to communicate with you. It is probably not a good idea to say thank you because the kids will learn that they can take that away from you." I thought about that for a long time. So now what I do is -- well, some of the kids sign better than others, so I will say: "Wow, I didn't know you knew the sign for that word. That is really good." We make it competitive in our family a little bit. This is really good for the father, too, because the kids will sign and I will say: "Wow, your dad doesn't even know how to sign that." He will be sitting there, and has to look that up in the dictionary. So the competition part is really good and really helps with communication problems.
8 Adjustment to Deafness

Steve Larew:

When we are talking about identity, there is no right or wrong answer. You have to decide for yourself which group you feel most comfortable with -- the hearing, the deafened, or the hard of hearing. This is a very personal decision.

I have been deaf for 27 years. For the first ten or twelve years of that time I called myself hard of hearing, even though the actual time when I functioned as a hard of hearing person lasted maybe for about two weeks. When I say hard of hearing, I mean that I thought that I could benefit from using hearing aids and lipreading.

I had been in the "hearing" world and still wanted to be a part of it. I knew nothing about living in a "deaf" world, and it is very frustrating to me, as I look back, to realize that it took almost three years before I received information on services available for people who are deaf. My parents took me to hospitals several times for hearing tests as they wanted to learn the reason I became deaf. Finally, a social worker gave me information about Vocational Rehabilitation.

After THREE years, I finally had information about services for persons who are deaf. I decided to attend Gallaudet College, now Gallaudet University, and continue my college education. I wanted to get a college degree, and I had not been doing well in regular college programs. I was trying hearing aids. I was trying lip reading. They were not successful for me. I have been trying to read lips for 27 years. I still can't do it. Hearing aids did not help me. I had to look for something that would work.

I tried sign language. Gallaudet, at that time, had about 1,000 students, and about 95% of them are Deaf and come from Deaf residential schools. They were fluent in sign language or American Sign Language (ASL). I showed up on campus and I could sign, "My name is S-T-E-V-E." That was about the limit of my sign language skills when I showed up at Gallaudet. And everybody else is going a mile a minute in ASL! I was lost.

At the same time, I didn't understand the deaf culture. Why, for example, do deaf people always pound on the table first before they sign? It took me months to figure out that they needed to get the attention of other people first. Only then could they talk in sign.

Hearing people shout to get attention. Deaf people bang on the table, stomp on the floor or flash the lights. All of this was new to me.

I did learn sign language at Gallaudet: Signed English. I have never become fluent in ASL, and at that time there was not much discussion regarding which type of sign language was better.
At Gallaudet, I learned to accept myself as a deaf person using sign language. Using sign language never bothered me. I could go out in public places and sign with my friends. My parents never resisted learning sign language. Of course, they have not become skilled in sign language, but they never resisted trying to learn. My parents took two sign language classes and my mother finger spells and uses simple signs. My dad prefers to write. My four brothers all took sign language in college, so they all know some sign language.

Eventually, having received my Master's degree in Rehabilitation Counseling, I began to work with people who are deaf. A friend, who went to graduate school with me, set up a self-help group for people who had become deaf, and I thought: "Why do that? Why do late-deafened people need help? Why?" I didn't understand the purpose for it. Why? I mean, I fought for myself. I went into graduate school. I made a career out of becoming deaf, so I didn't understand.

So, I didn't go to that first self-help group. I felt comfortable as a deafened person, and didn't understand why other late-deafened people didn't feel as comfortable as I did. But about two years later, I kept hearing about this group, ALDA. I kept hearing about this person named Bill Graham, and finally I got up the courage to go to a picnic at Bill's house.

That is how I first got involved with ALDA, I found that this was the group where I was most comfortable. I am at the stage where I feel comfortable with deaf people. I feel comfortable with late-deafened people. One of the things that I like most about ALDA, is that communication for us is whatever is successful for each one of us individually. Whatever works for you is correct, and we all make our own decisions on that. In the end, you have to decide for yourselves on how to identify yourself. There are no right or wrong answers. You have to decide for yourselves where you feel most comfortable, and how you want to describe yourself. You are here at ALDAcon, so you are to some extent relating to the term late-deafened. I think most of you feel comfortable here. I hope you do.

But, you can't stay inside your house for 12 months and wait for next year's ALDAcon. You have to find other places where you feel comfortable. The decision is yours.

Becoming deaf can be a positive experience. Get out and be involved in some way. Do different things. Explain to people about your deafness. Explain to people what your needs are. That's important. Feel comfortable with yourself. It is essential individuals who are deaf or late-deafened feel comfortable. Don't feel negative about it. Talk about it. Find other people, and talk about it. It doesn't have to be another late-deafened person. Many times the late-deafened person understands your feelings better, but it can be a hearing person who is sensitive, or a hard of hearing person who is sensitive.
All of these things will help you to begin to feel comfortable with yourself. Don't apologize. Do not say "I am sorry. I am deaf." I still make that mistake. I still say that many times. It's important that you not feel negative because you are deaf.

Mary Clark:

I just wanted to add that once I realized what my identity was, I felt so much better. It was like I could accept who I was and what my issues were. It is interesting because I told you about my family thinking of me as a person with a little bit of a hearing problem, and that the attitude was that we weren't going to get upset about it. That's how I explained it to myself, even after I became totally deaf. I said: "Well, I have a little bit of a hearing problem." Well, gosh, I really couldn't understand anything! But I was using, at that time, the feedback of my family to define myself.

I still remember a day when my husband and I were working on the lawn. A neighbor came over and started talking, and, of course, I couldn't understand, I just let my husband and the neighbor chat. I saw my husband cup his hands over his mouth and whisper: "She has a little bit of a hearing problem." It was then that I realized: number one, he was embarrassed, which in turn made me embarrassed. Number two: I had a little bit of a hearing problem. And I began thinking: this doesn't match somehow.

So again Jeff and I sat down, and I said: "You know, this definition of the problem doesn't work for me anymore. I don't have a little bit of a hearing problem. Also, your body language is indicating embarrassment which makes me feel embarrassed about myself."

This was a turning point. Until then I was very influenced by how other people dealt with me. When I finally was able to feel like I was accepted by the family, and that my deafness was not embarrassing, and that we could all talk about it in a positive way -- then I actually became better in all situations, both with my family, as well as socially with those outside the family.

Steve Larew:

In closing, I just want to say a bit about competent professional assistance. How many of you feel you received good information the first time you went to an audiologist or doctor and they told you had become deaf? Did you get good information? No, I didn't think so. The first time I went to an ear doctor, he asked me if my deafness might not be psycho-somatic to get out of going into the army. The second question he asked me was if I was smoking bad marijuana. Thinking, perhaps, that was the reason that I had become deaf. The answer was no, I was not smoking marijuana at that time. No. The answer was no. He had checked my ears, but could not find anything wrong, so he was looking for other reasons why I had become deaf.
Did he tell me about vocational rehabilitation? Did he tell me about Gallaudet? Nobody of the ear doctors or audiologists I went to gave me good information about any services for the newly deafened.

Too many times professional people label people. "Oh, you have become deaf. Go to sign language class and then you will be able to function as a deaf person." That is not going to work! Learning sign language is not going to help you accept yourself as a deaf person. Learning sign language will not help you deal with all the emotional feelings that you have at a time like that. Mary and I talked about ourselves and our experiences. You probably have had similar feelings and experiences. You may have had different feelings. The idea, though, is to remember that becoming deaf is a major life change that will take time to adjust to. So we need to talk about these issues, and we need people who know how we feel.

Learning sign language by itself is not going to allow you to accept yourself as a person that is deaf or late-deafened. It may help. Sign language can be part of the answer. Sign language helped me a lot. But at the same time, I am not going to say that learning sign language is going to help you. That is something you have to decide. If you want to learn sign language, great. But if instead you feel most comfortable using lip reading, that's OK too.

This is something we have to do for each other. I am not a good lipreader. We must accept, and work with, each other's different communication needs, whether it is signing, lip reading, writing, assistive listening devices, or hearing aids.

Understand especially, that hearing aids are not going to help everybody. Many people feel that new technology and cochlear implants will, "solve hearing problems." Well, maybe they will. Maybe they won't. As for myself, I am reluctant to try an implant because I don't like the idea of going into a hospital and having a doctor fix my ears. I hate hospitals. I prefer just to stay as I am. That is my choice. Accept that for yourselves. I did.

Don't label yourselves and don't let professional people label you. You have to decide for yourselves what will work, what you want to do. If you want to learn sign language, do so. There are many places you can learn sign language. If you don't want to learn sign language, that's fine. You have to deal with the communication issues that YOU have, and decide how YOU can best answer them.
CREATIVE WRITING TO COPE WITH HEARING LOSS AND OTHER LIFE ISSUES

Mark Dessert

Introduction: This paper will describe the use of creative writing as an adjunct to identifying and dealing with anger, grief, denial, depression, and other negative aspects of adult onset hearing loss. Even though someone may be consciously aware of anger or grief in the moment, it is human nature to push uncomfortable issues to a "back shelf" of the mind. Creative writing is a non-threatening method of bringing those issues into conscious awareness where they can be identified, evaluated, and decisions made to deal with "unfinished business." Major points will include the value of keeping a personal daily journal, the basic structure of a good essay, and combining the intimacy of a personal journal with the art of an essay to set oneself free.

Creative writing can be used to cope with hearing loss and other life issues. It is a valuable tool that anyone can use no matter who they are, no matter what their writing experience is, no matter what their life experience is. It is something that can be used to learn how to deal with emotions such as pain, anger, depression, and frustration -- emotions which are so often present with hearing loss.

I would like to share a bit of history with you. Most of us know what it's like to deal with new hearing loss in our life and all the frustration and pain that accompanies it. About nine years ago I discovered how writing could help me work toward my goal of feeling better about myself.

I belonged to a community support group called Adult Children of Alcoholics (ACOA). In that group I had two very special friends who were making real progress in their lives. Each week they would come to the meeting and share the wonderful things that were happening in their lives. They had each started keeping a daily journal and would make time every day to write down all the things that happened to them. Keeping a journal seemed to give them a better perspective on how they were interacting with the world around them. Over the three years I belonged to that group, I saw my two friends make tremendous strides in becoming able to manage their lives, and deal with the issues that were interfering with their happiness. This started the gears turning in my head.

Learning through writing isn't easy to explain; it's something you need to experience, and my goal here is to share with you what I learned, and, hopefully, to motivate you to start using some of these tools in your life. Why? Because this is something you can do. It
requires a commitment of just a few minutes a day to get started, and I want to encourage
you, if you have never written a daily or personal journal, to start doing so.

When you make a commitment to keep a daily journal, it gives you quiet time for yourself.
That's something a lot of us neglect. We have our work life, and our family life. But it is
hard to find time to be really good to YOURSELF. If you commit to taking at least fifteen
minutes a day, perhaps before you go to sleep, to write in your journal, that is a gift you
would be giving to yourself.

A daily journal brings your thoughts and feelings to conscious awareness. Often when
things happen to us, we respond on an emotional level, not on a conscious, thinking level.
We don't, even though it may generate a very strong response in us, really stop to consider
what is REALLY happening to us. When we start writing in a daily journal about things that
happened to us today, or yesterday, or last week, then we find that we have a reason to
think about what is going on, and soon we may start thinking about our lives in a different
way.

A daily journal helps us to collect your thoughts. Our life is a continuum and different areas
of our lives just kind of melt and flow together. It's hard to see it all in one picture though
unless we give it structure -- and the journal gives us that structure. Using it, for example,
we can come to realize that the disappointment that we had at work last week is affecting
other areas of our lives. Used properly, it can be virtually a road map to chart our way
through life; enabling us as it does, to look at the choices we have made and how we feel
about them.

I have been asked how to write in a journal. How often? When should you read what you
have written? There are no set answers. Write as often as you like, and go back to it when
you feel comfortable -- right away, or six months later. The action of writing in the journal
will change the way you remember what you wrote. Every once in a while I go back and
review parts of it, which in turn helps me to see what other parts I want to review. Everyone
develops a very individual technique.

There are two kinds of journals. The personal journal is what keeps you "in the now" about
what is happening in your life today. There is, in addition, another type of journal that I find
valuable called "A whole life review" journal.

During my Junior year internship in college, I worked with an elderly deaf population:
women in their 70's and 80's who were very much aware they were approaching the end
of their lives. One of the activities we engaged in was to do a whole life review. This is a
valuable technique social workers use with elderly people because it helps their clients put
the pieces of their lives back in place and attain some satisfaction with their lives. Soon I
realized that this technique could also help me, and I started writing my own whole life
review journal, using the same techniques I used with my clients at the senior citizens
center.
In writing a whole life review you start with your earliest memory and then work forward. You may remember something that happened at age fifteen -- a first date perhaps. This in turn will bring back another memory that happened a year or two earlier, and so on. Bit by bit you add memory after memory until a picture is formed. Doing a whole life review such as this, helps us to reorganize and reintegrate what is troubling or preoccupying us. It helps us to unravel the confusion of our lives by returning to consciousness past experiences -- especially those that involve unresolved conflicts. In your whole life review journal, you will be able to reach back into your childhood, your adolescence, and early adulthood, and begin to think for the first time about issues that made you the person you are today.

A whole life review journal is basically a documentary mini-series about your life. You are not writing it; you are simply reconstructing it. You spent the last twenty, thirty, forty, or more years writing it in cooperation with everyone else who touched your life. Now you are just recording it on paper so you can review it. It is a powerful tool for learning how to cope with hearing loss and all the other issues, both positive and negative.

The whole life review journal gives you a safe place to record family history. I don't need to tell you that our families, whether our birth families or families we constructed ourselves, have a major influence on developing our core beliefs from which we define our identity. Exploring our family history gives us a more accurate picture of who we are rather than just making assumptions about who we are. It also enables you to confront and accept things that happened to you while you were growing up.

Keeping a daily journal and a whole life review journal are non-threatening ways of taking action to make changes in our lives. It is especially non-threatening if you keep your journal confidential and don't show it to anyone. That way, no one will be able to criticize you.

Writing in a journal is a wonderful tool because it is a safe tool for you to use. But none of us get anywhere by being safe. We have to take risks every day. Nothing of value comes in life without risk. The next step after you've been writing in your journals for a time, is to take the risk of writing with the intention of showing your work to others.

There are a couple of steps involved. The idea of sitting down to write an essay about something very intimate in your life that you will share with others is a wonderful affirmation because you are taking action to do something you don't normally do. When you start approaching an action that most of us aren't comfortable with, that is a wonderful affirmation. When you start writing for other people, you discover that the action of writing an essay about an intimate occurrence in your life connects you to a source of inner strength we all have but might not be aware of. We need to learn how to use it, how to tap it.

We humans are not solitary animals, we are very social creatures. In spite of that, we tend to fear intimacy. Men, especially, are very much afraid of intimacy, and hearing loss
presents a major challenge to sharing intimacy. When I write for people I don't know, or
don't know yet, it is without the frustration that accompanies trying to communicate verbally
with hearing people.

If you show your essay to someone and they are critical about it, they are the wrong person
to show it to. Go find the right person, someone who is interested in who you are, instead
of the mechanics of writing. You see, that's the risk that's involved; as mentioned earlier,
nothing of value comes in life without risk.

SUGGESTED READINGS

*Bird by Bird* by Anne Lamott is wonderful. Anne Lamott has an entertaining way of showing
you what the life of a writer is all about.

*If You Want to Write* by Brenda Ueland who spent her life teaching people to write. She did
not just teach people how to write, she taught them why they should write. When you read
her book, you discover why you should share your stories with others.

*The Book of Qualities* by Janet Ruth Gendler, has nothing at all to do with writing. It is a
wonderful, whimsical perspective on who we are in terms of our feelings.
I have to admit it. I'm terrified of going to the hospital. Not because I'm afraid of needles, nurses, doctors, or even those ridiculous hospital gowns. What really scares me is that I can't hear anymore. Hospital staff might as well speak Swahili because I can't understand a word they're saying.

In April of 1997, my concern about late-deafened people communicating with hospital personnel went from theory to reality: for the first time since I went deaf seven years ago, I had to go to Georgetown University Hospital for surgery to replace some tubing that had been inserted in my brain in December of 1990. And I was scared. Not so much because of the surgery, which was performed by a doctor who is considered one of the best neurosurgeons in the country, but because I didn't know how I'd communicate with hospital staff now that I can't hear.

Good news. The surgery and the communication thing both went well. Figuring I should share what I'd learned from my hospital "fun" with other late-deafened people, I led a workshop about communicating with medical people at ALDacon '97. I had the good fortune to be joined for the workshop by three wonderful people: my wife Mary, my good friend Larry Littleton, who lost his hearing at a young age and graduated from the National Technical Institute for the Deaf at Rochester University, and ALDA's marvelous 1996 president, Robin Titterington, who's had more than her share of medical "adventures" since becoming deaf. Obviously can't talk about everything that happened at the workshop in a single article without making it go on and on, but here are some tips.

For starters, remember that the Americans With Disabilities Act (ADA) makes it a lot easier than it used to be to get an interpreter or necessary accommodations in a medical situation. But invoke the ADA as a last result after you've tried everything else. Start by asking for what you need in medical situations. You'll be surprised at how often you get what's necessary. Remember, as the old saying tells us, and say all too often, you catch a lot more flies with honey than vinegar. Start by asking politely for reasonable accommodation, and if the answer is still "no" after repeated attempts, then remember that the law is on your side, and don't be afraid to use it.

Regardless of the ADA though, it's a good idea to do whatever you can to make your stay as painless (sorry for the bad pun) as possible before you enter the hospital. I started by making up a sign for my hospital room letting people know I was deaf, but not dumb by a
long shot. I can't count how many smiles that got. In fact, my doctor liked it so much he made a copy of it and put it in my medical file.

I also made up a slew of cards I put in a pocket on the sign explaining how people should communicate with me. The main point the cards made, and one that I imagine applies to most late-deafened people, was that I NEEDED THINGS WRITTEN DOWN. Apparently, that worked: one of the nurses in my ward said I should "talk" as much as I wanted and they'd make sure I always had plenty of paper to give to doctors, nurses, and hospital staff to write down their answers.

Another thing you might consider: about a week before I was admitted to the hospital, I talked by relay with the director of patient relations. More and more hospitals have those now, and it's a good idea to talk to the one at your hospital before you're admitted. I told mine exactly what I would need, both before and after the surgery, and she not only made sure I had everything I needed, but turned into a great advocate for me as well.

The other people on the workshop panel were a big help too. My wife Mary, a certified interpreter for the deaf, talked about being the spouse of a late-deafened person going in the hospital. Besides being a great advocate and a super interpreter, she was also a human being with feelings and emotions. She had a lot of other things on her mind besides interpreting for me when I was a patient, so we asked the hospital to provide me an interpreter for before the operation. That way she wouldn't have to sign for me at such an emotional time. And the hospital came through, with no problem!

Larry provided us with a totally different perspective. Like me, he's in a marriage with a hearing woman, but he talked about the flip side of the coin: what role should the late-deafened person play when a hearing spouse or loved one has to deal with the medical world?

He spoke from first-hand experience. A few years ago, Larry's hearing wife Susan went into the hospital for outpatient surgery that was supposed to last two hours. During the surgery, though, the doctor came out and said, "We're having problems; she has to stay." Larry asked "Where is the interpreter?" to which the doctor replied "You can read my lips." Larry asked the doctor "Would you like me to do surgery on you?" "No," came the reply. "Then get me an interpreter," Larry said. And he got one, reminding us all that sometimes it's essential to be assertive to get the accommodation we need.

That doesn't always mean asking for an interpreter, even if you're comfortable with one: hospitals have computers and lots of staff members who can type. The law entitles you to reasonable accommodation, and the important thing is getting what you need.

Before we asked for comments and questions from the floor, Robin, who has been having more than her share of medical challenges lately, mentioned that the medical situation for late-deafened people has improved considerably in the last ten years. Then, to prove it,
she talked about her experience a decade back when she asked for an interpreter for her evaluation for dialysis, and how much different things have been for her in recent medical situations.

We also "heard" lots of comments and questions from audience members. And they all came down to the same thing: being late-deafened doesn't mean you have to settle for being a second-class citizen. Communication access is your right. And you don't have to work your tail off in an effort to understand an interpreter if you're not comfortable with one, either. Get what you need. After all, you have a right to it. And as former U.S. Attorney General Ramsey Clark once said: "A right is not what someone gives you; it's what no one can take from you."
DISCLAIMER: The information provided here is not all inclusive and should be relied upon for educational and discussion purposes only. It is not intended to replace the independent judgment of a medical doctor.

Neurofibromatosis Type 2 (NF2) is a complex, unpredictable and often devastating disorder. Medical treatment for NF2 has advanced significantly in the past few years and the purpose of this workshop was to share the medical experiences of a three-member panel. This workshop presented a brief history and summary of microsurgery and radio surgery techniques available for treating NF2 acoustic neuromas (AN). Afterwards, three panel members shared their personal experiences on NF2 treatment with the audience. Because of the complex nature of the NF2 tumors, only acoustic neuroma tumors (more correctly called vestibular schwannoma) were discussed. When discussing medical treatment for acoustic neuromas (AN), it is important to understand the difference between the unilateral AN and the NF2 AN. There are three important differences:

1. The NF2 tumor is more difficult to remove because it tends to grow within the nerve. Not only is the NF2 tumor more "stuck" to the nerve, it becomes part of the nerve. The unilateral AN on the other hand tends to grow on the nerve sheath and compress the nerve.

2. The NF2 tumor generally allows some neurons to function for a longer time. This may result in the tumor growing to a large size by the time the patient notices any symptoms. The unilateral AN results in compression of the nerve which affects the nerve function and the patient may notice symptoms when the tumor is smaller and easier to remove.

3. Many doctors find the NF2 AN is more vascular. Therefore, the risk of bleeding during surgery, with associated complications, is greater.

For these reasons, close analogies to NF2 AN removal and unilateral AN removal cannot be made. These differences in the two types of tumors also make the NF2 tumor more difficult to treat, both by microsurgery and by radio surgery.
MICROSURGERY

The first AN to be successfully surgically removed was in 1894. This was a partial removal only and the first AN to be totally removed was not until the 1920's. Surgery results made steady improvement over the years but were still far from satisfactory. In the early 1960's, microsurgical techniques were gradually introduced. These techniques are continuously improving and are still used today. The advent of the CAT (Computerized Axial Tomography) scanner in the 1970's and MRI (Magnetic Resonance Imaging) in the 1980's greatly improved microsurgery results by allowing the surgeon to be able to diagnose the AN at an earlier stage and therefore able to operate sooner when the tumor is smaller and easier to remove. Different microsurgery techniques (i.e., Middle Fossa, Sub-occipital, Trans labyrinthine, etc.) were developed for AN removal, each with its own set of advantages and disadvantages. For example, the Trans labyrinthine technique generally allows the doctor good access to the tumor location. However, there is no chance of hearing preservation in this technique.

Despite significant improvements in microsurgery, the surgery often results in deafness. A subtotal removal or decompression can sometimes increase the chances of hearing preservation but both of these techniques will likely require additional surgery at a later date. In a subtotal removal, only part of the tumor is removed. This increases the chance the auditory nerve will remain functional after the operation. A subsequent operation is usually required for continued removal of the tumor because sub-total removals tend to regrow. In tumor decompressions, the doctor will not remove any of the tumor, instead bone surrounding the tumor is removed to relieve pressure. This will allow the tumor to continue to grow and the continued function of the hearing nerve. Thus, a tumor decompression will allow the hearing nerve to function for a longer period, but will require an additional operation to remove the tumor at a later date.

When hearing is lost due to surgery, the patient may wish to have an Auditory Brainstem Implant (ABI). An ABI can be implanted at the time of surgery when it is known the tumor removal has resulted in deafness. Although the ABI will not allow the patient to distinguish speech, it does give the patient a sensation of hearing which generally aids in speech reading and identifying sounds. However, the ABI is still considered experimental and does not always work.

RADIOSURGERY

In 1951 a Swedish neurosurgeon presented the idea of having a large number of converging beams of radiation crossfire a target in the brain. He coined the term radio surgery to describe this concept. Radio surgery differs from conventional radiation therapy. In conventional radiation therapy, a large area received the radiation dose. The first device based on the radio surgery concept was called the Gamma Knife. A prototype Gamma

1 "The ABI is an implanted device which causes electrodes to stimulate the auditory brainstem giving the patient a sensation of sound."
Knife was constructed in 1968 and the first patient was treated in Stockholm, Sweden in June 1969. Although the Gamma Knife has been in existence for almost 3 decades, it has only been in the last decade that it has had world wide acceptance.

Today's Gamma Knife machines consist of 201 permanently mounted Cobalt 60 sources arranged spherically around the patient's head. These sources emit gamma radiation, which act by deranging the tumor molecules so that they can no longer reproduce and eventually die. The Gamma radiation is aimed at a point of focus (ie., the tumor), and although each individual beam is relatively weak and does not cause detectable biological effects, the radiation at the point of focus is very powerful.

The long term effects of gamma radiation, and radiation in general, are not clear. The Gamma Knife is often referred to as Stereo Tactic Radio surgery and it's successful use has led to the development of other radio surgery techniques. Some of these are:

**LINAC**: Linear Accelerators (LINAC) were initially designed for radiation therapy of cancer. Like the Gamma Knife, LINAC is Stereo tactic Radio surgery but unlike the Gamma Knife, they emit high energy X-rays. LINAC Radio surgery can be given as a single treatment or in multiple treatments.

**FRACTIONATED RADIO SURGERY**: In Fractionated Radio surgery, the patient receives the radiation in a series of doses. The idea being that the normal tissues have some time to recover after each dose.

**INTENSITY MODULATED RADIATION THERAPY (IMRT)**: IMRT is a relatively new Radio surgery technique and was first used in March, 1994. The patient is treated with many very small beams. Each beam can have a different intensity. IMRT is sometimes referred to as Peacock treatment.

This concluded the introduction to NF2 medical treatment.

The panel members then each answered two questions. Their first question was to describe their NF2 medical history.

**Panel Member 1**

Panel Member 1 lives in Chicago, Illinois. After learning she had an acoustic neuroma in 1982, she went to a well known medical center for her operation. The tumor was removed without any major complications. She became deaf on the side that had the surgery and returned to Chicago. Four years later, she noticed a hearing loss in the other ear. She went back to the medical center and they performed another CAT (Computerized Axial Tomography) scan. The CAT scan showed no tumors. They suggested the panel member see a neurologist. She saw a neurologist in Chicago. The neurologist did diagnose a second AN, and the tumor showed up clearly on the MRI (Magnetic Resonance Imaging).
scan. She took the MRI scan to the original medical center. At the medical center, they told her they did not have much faith in MRI scans. (This was the mid 1980's when MRI was first introduced.) Her hearing was still good in the ear and she decide to postpone the operation until 1990 when her hearing dropped considerably.

She had the surgery in Chicago and the doctor was able to save the facial nerve but not the hearing. She is now totally deaf, but has had no further NF2 complications.

Panel Member 2

Panel Member 2 lives in Pittsburgh, Pennsylvania and had her first AN removed in 1975. At this time, she suspected she had another AN on her other ear and NF2. However, she was led to believe she only had an unilateral AN. Four years later in 1979, she asked for a follow-up check although she had no symptoms that would indicate any problem. In the checkup, a large re-growth of the tumor appeared on an MRI scan. This re-growth was subsequently removed. Ten years later in 1989, she had another MRI scan for an unrelated problem. The MRI scan revealed something on her good ear. The doctors were not clear on what it was but assured her she did not have NF2. After seeing a number of doctors who all agreed she did not have NF2, she saw a geneticist. The geneticist also told her she did not have NF2 but sent her MRI scans to another doctor. This doctor finally made the NF2 diagnosis. After learning of the positive NF2 diagnosis, her hearing remained relatively good until 1996. At this time, she decided to have a decompression thus giving herself more time without becoming deaf.

Panel Member 3

Panel Member 3 lives in Berkeley, California. Like Panel Member 1, this panel member went to a well known medical center for his surgery. He had the right side tumor removed in 1982. He retained some hearing in the right ear after the operation and there was minimal facial nerve damage. The left side tumor was removed the following year in 1983. This resulted in deafness in the left ear and left-side facial paralysis. He was under the impression that the tumors were both totally removed. He went on having follow-up MRI scans.

In 1992, a MRI scan revealed tumor re-growths. The MRI scans were sent to his doctor but the panel member was not informed of the tumor re-growths. It was not until 1995 that a local doctor informed the panel member of the tumor re-growths and said something had to be done. The panel member was surprised to learn of the tumor re-growths. Not wanting microsurgery again he researched other options and decided to undergo fractionalized radio surgery in 1996. The doctor performing the fractionalized radio surgery felt there would be no facial nerve damage but also that he might not be able to save the hearing that remained on the right side. This is what happened. The panel member currently has a small amount of hearing but not enough for a hearing aid to help.
The second question for the panel members was: "What do you feel is the most important thing you have learned regarding the treatment options for NF2?"

Panel Member 1

Panel Member 1 started her NF2 surgery at a well-known medical center. She assumed the doctors were very competent to the point where she almost did not question them. However, something did not seem quite right to her. The doctors did not appear confident in what they were saying. When she returned home and talked to the doctors there, she realized there could be many different opinions. She feels it is important to be informed about NF2 and to do what feels right to you to do.

Panel Member 2

Panel Member 2 feels the individual must decide what is important to them and choose the medical treatment which best aligns with their own personal circumstance. There is no best solution for choosing a particular treatment option. The right answer may be very personal. For example, an individual may opt for radio surgery because they do not want to go through the "hell" of microsurgery. Another individual may opt for microsurgery because they do not want to worry about any long term effects radio surgery may have.

Panel Member 3

Panel Member 3 feels there is so little the doctors seem to know about NF2. As patients, we have gone through NF2 and we have researched it. The treatment option selected is a matter of individual choice. Patient research is important because the doctor will generally tell you only his/her specialty area. For example, the first doctor the panel member saw was skilled in microsurgery but knew very little about radio surgery. It follows the doctor would promote microsurgery. This panel member feels there is a vast amount of knowledge among our NF2 peers and particularly on the Internet group 'The NF2 Crew.'

He was not hesitant to tap into this group for medical discussion and support. This concluded the workshop presentation. There was some time available for a question and answer period from the audience. A point to note is that all three panel members experienced problems in the course of their NF2 diagnosis. Panel members 1 and 2 were not initially diagnosed with NF2. Panel member 3 was not informed of his tumor re-growths. In-line with what the panel members have concluded, it would appear there is no substitute for NF2 patient involvement in their medical diagnosis and treatment.
SURVIVING FAMILY GATHERINGS

Cheryl Heppner and Fred Heppner

Part I

We often hear from people who want to know what strategies work for other families with a late-deafened member. It is also valuable to share what strategies don’t work so that all of us can learn from the mistakes of other people. We have condensed and edited selected comments made during the workshop, and hope that others will benefit from the insights shared.

Finding What Works and Setting the Stage for Success

- Sometimes I try to take people one-on-one and talk to them. This is the main thing that works for me as I have pretty much given up on trying to understand in a group situation.

- I take the time, before dinner or after, to sit down one-on-one to talk with individual family members, because I can handle that.

- We have an unwritten rule in my family that the deaf person picks wherever he or she wants to sit, this gives me the freedom to talk to people without having to constantly ask people to move. The people in my family have accepted this.

- If there is something going on that I feel I want to be involved in, then I find some imaginative way to get involved. It could be a game or cards or just talking one-on-one with someone. At other times, I feel free to tell them, no, I just want to sit and read, and enjoy myself because I don’t feel like communicating right now. And they accept that.

- I focus more on those family members willing to learn to communicate with me.

Adjusting Your Attitude

- I lost my hearing recently so the holiday was the first time I saw my family and my partner’s family as a deafened person. It was new for everybody and very difficult. I discovered humor will help them adjust to my communication needs.

- One thing that I learned was that if I can keep my positive attitude, and show that I want to be engaged, then it helps them keep trying to communicate with me.
28 Surviving Family Gatherings

- If I can't avoid situations that will make it hard for me to communicate, I go in with very small expectations. I accept that I will be there, I will see people, but I probably won't be able to understand what they say.

- I found it helped to accept that I will never always know what everyone is saying around a large table.

- It is easy to have high expectations because of family traditions. When we could hear, we looked forward to family events. Why should they change now that I have become deaf? I think part of it is that we expect to have free and open communication with everybody, and I think that might be expecting too much. I would be satisfied to have communication with a smaller number of people. There are people in my family I will always be able to communicate with, and I am satisfied with that.

Reminding Your Family of Your Needs

- My family gets together and we sit around the table. They know that I don't understand, but I want to know what is going on. I say, "What are you talking about?" It is my responsibility to ask.

Using an Interpreter

- I try to bring someone to interpret for me -- a friend, my wife, somebody, and that helps, too.

- I have hired interpreters for family gatherings. It was wonderful. The first few times we had people who sign in the house, my family was not crazy about it, but the last time we had a big party, we hired an interpreter. They really loved it.

- The one time we used the interpreter, it was for a big family gathering. I told them I would not come unless there was an interpreter. I offered to pay, and they made the arrangements, and they never sent me the bill.

- In our family, we share the expense for an interpreter.

Wearing a Visual Reminder

- There are shirts you can wear that have rules you are supposed to follow in communicating. I got mine at ALDA-Boston.

Using Technology

- When you lose your hearing, it affects the family. But it isn't a static thing -- it's a dynamic. Everyone has to learn. The deaf person has to learn to adjust, and the
hearing people also have to learn to adjust and understand. We didn't do that in our family for quite some time and drifted apart. I made an effort to reach out to my children, who are now grown. I sent them each a text telephone for Christmas. Now I call them, and they call me.

- E-mail has helped me get closer to my family.

- A friend of mine went to a doctor, and she couldn't understand him, and it was frustrating for her, because the information was very important. She told me that she went to Radio Shack and bought a unit that would record his conversation. Then she took it to a secretary to type out. I thought this was an excellent idea, and I'm going to buy one and put it on the dining room table so that afterwards, even if I can't respond spontaneously, at least I will know what transpired.

Making Attendance a Choice, Not a Requirement

- My husband and I are more selective about which gatherings we choose to go to.

- I made a few choices in my life. One was that I chose different ways that meet my communication needs, and not my family's communication needs. We don't get together much.

- Some people have filled in the void and had a rewarding family experience by creating their own "families" of friends who support them.

Expressing Your Feelings

- For almost 40 years, my mother hasn't understood what it means for me to be deaf. Then I bought Cheryl Heppner's book, "Seeds of Disquiet," and gave it to her. I found that writing a letter to my family, and telling them how I was feeling, made a difference.

- Our recent family get together was at a home with tall cathedral ceilings and a huge living room. We were scattered around in groups of two or three. I was usually off in a corner somewhere. They thought I wanted to be by myself because "We know you love to read," so we stopped communicating with each other. They apologized when I talked to them about it.

- Some people have talked to their families. Reactions from the families were mixed. Some felt it was the deaf person's problem, not theirs. Some came up against true culture clash -- Native American tradition is that you do not make eye contact with elders but are expected to look down to be respectful.

- My family philosophy was that if you have problems, you keep them to yourself. You solve your problems yourself. So I had the idea that deafness is my problem and I have
to solve it myself. Now I have a close friend who keeps encouraging me to talk to my family. Through her, I am now learning to open up and tell them what I am concerned about. It is getting better.

- In the past, it was really difficult. The kids would be walking down the stairs or out the door, talking, and I of course wouldn't know what they're saying. But now, since I opened my mouth, and told them what some of my needs are, it is getting much better. Of course, they are all grown and that helps too.

**Exposing Your Family to ALDA and Other Deafened Adults**

- I have a cousin who I see only occasionally. One day I sent him a mess of ALDA newsletters. Not only did he read them, but I got the sweetest, most unexpected note of apology, saying, "You are probably too tactful to say this, but I realize I have been just as insensitive as those clods that people are writing about in your newsletter." The next time I saw this cousin, at a big family party, the first time I couldn't understand something he said to me, he grabbed a pen and paper. I was astounded! He is the first person who knew me since the days when I could hear, who ever did that, let alone without my asking. Constructive change on the part of family members is possible.

- I am giving gift memberships in ALDA to some of my family. That has helped some.

- My mother is also very hard of hearing, so that helps, and the family knows about hearing loss. My aunt was hard of hearing, and my grandfather was hard of hearing, so deafness is not new to the family. It is still a struggle, but I do have an advantage to have a little Deaf culture already in the family.

- Taking a family member to an ALDA meeting can be a real eye opener. Since they don't have the experience of being deaf, they often don't realize how deafness shapes who you are.

- Last Christmas, a relative was visiting me, and I took him to our ALDA party. He said he never realized how much fun we had together. He went back home and paid for a tutor to learn sign language. Yeah!

**Difficulties Faced by Hearing Family Members**

- My brother is deaf and I am the only one in my family that can sign. When we get together as a family, there is a lot of pressure on me to interpret. I don't know how to deal with that. When I'm not there, they are isolated, and when I am there, I am the only channel of communication with other members of the family.

- My wife gets upset at the dinner table when the family's attitude is that their talk is just little chit-chat, and really not that important. They say if they have something important
they want to talk to her about, they will do it on the side. She tells them it’s the little things that she misses; the little subtle cues that go on that lead to the more important conversations. However, they don’t seem too eager to try to help her with that.

- I don’t care if they rely on me for interpreting, but if they ask me to tell my spouse something, I say "Tell it yourself." I refuse to do that. I will interpret, if necessary. But I can’t be interpreting 24 hours a day.

- One deaf relative has children who are hearing and relies on them to interpret telephone calls. When they call, I will talk to the children about their issues, but if they start interpreting what the mother is saying, I say "Put your mom on the TTY." I don’t think we should put that kind of pressure on children.

- Asking hearing children to interpret for a deaf adult is a very serious issue for a lot of families. Another issue is that when one parent becomes deaf, the hearing children have a tendency to go to the hearing parent for all of the communication. Sometimes the family feels they want to protect the deaf person. They think the deaf person has enough to deal with. This has a big effect on the children. We know from research and from talking to children of deaf adults, that it can affect the child’s identity as the child is made to become the adult, not the parent.

- It’s difficult for a child to ask people to talk with a parent directly. As an adult, I can tell people what to do, and they may not do it.

*Profound Thoughts -- And Humor*

- I always thought that the ideal situation would be an immediate family exchange program where, when a person reached age 21, they would trade in their family of origin for a whole new one -- give their birth family to somebody else and kind of start fresh as adults.

- From the time my children could talk, they were told to get my attention by touching me. I would always look at them before they talk to me. And they have done it all their lives. Recently I had a cochlear implant and now I don’t have to look at them every moment, but they will not talk to me unless I am looking at them. It’s become a habit.

- We mix things up a lot. Sometimes I go to my family events with my husband and sometimes one of us goes alone. We had a problem with both families wanting to rely on my husband to interpret for me. Now that they don’t know who is going to show up, it’s forced them to have to learn to communicate with me more.

- As far as expectations, I never know what’s going to happen. So I always bring a roll of Tums for an upset stomach!
Every family has a sort of culture. There are things like values and traditions that shape how they do things. A lot that happens when you become deaf challenges these traditions because we need to change how things have been done in the past. We have to either figure out ways to change the culture, make it more flexible to include us, or we can give up and walk away.

If you're married, you have two different family cultures to work with. It's a challenge, but the important thing to remember is that what people have already learned, they can unlearn.

It happened quite by accident that I set up a meeting without realizing it on a holiday weekend. My hearing husband was unhappy because he wanted to be together with my family. So I thought "there is no rule that requires that I have to be there for him to visit my family!" I knew my sister and her husband were driving up, and made arrangements for him to join them for the five hour drive. The whole family was together, without me. They had a fabulous time. I also had a fantastic time with my friends. The neatest thing about that was that my husband, my sister, and my brother-in-law played CDs all during the trip up and back, having a contest to see who could guess the song and the singers. They really enjoyed it, and that never would have happened if I had been there.

CODA (Children of Deaf Adults) is a good resource. You can find information on the web. Their national headquarters is in California.

Families change -- we lose some people, but we gain some, too. In my family, the only one that signs well is my sister-in-law, whom I met after I became deaf. Sometimes our families add people who have different attitudes and that helps.

One roadblock is that some families are not as committed or motivated to change as other families. A lot of agony comes from struggling against the feeling that your family doesn't love you enough because they don't change. But we can't know what's happening in each other person's life that prevents them from doing everything we need for them to do. It requires a lot of love and patience and persistence.

Part II

A Summary:

Here are some options and strategies you can use for family gatherings. They are not intended to be a guide but to spark ideas of what might work for you. We are extremely grateful to those who have shared their family stories with us.
Three Important Things to Remember:

1. No two families are alike. You may be single. You may be married, but not have children. You may be a parent or grandparent. Your extended family may be pretty set in its ways or willing to be adventurous. Family members may have other disabilities (e.g. arthritis, poor vision, learning disabilities, attention deficit disorder) that make some of the strategies less useful. What works for one family may not work for another family. Your family will have to make its own decisions on what is comfortable and fair.

2. Be creative. Don't get bogged down with unrealistic expectations. Modify or drop traditions that keep your family from communicating effectively and enjoying each other.

3. Model the behavior you want. If you want everyone to sign to you, sign when you talk to them. If you want them to speak slowly and clearly, be as slow and clear as you can when talking to them.

Strategies:

1. If you can afford it and know enough sign language or cued speech to benefit, hire an interpreter or transliterator. It's harder, but still possible, to hire a CART reporter or have someone summarize what is happening by a form of Computer-Assisted Note taking, typing on a computer.

2. Tell your family members that you want to get to know each better because they are all so interesting. Set up things you can do one-on-one. Most people enjoy the individual attention.

3. Bring a friend you can communicate easily with and want to get to know better. A friend can give you support and empathy when you have difficulty communicating. He or she can give you a person to talk with when you feel left out. And with this friend, you can help model the communications behavior you would like to have from other family members.

4. Go to family gatherings, but make sure your expectations are realistic. Set small goals that you can feel good about achieving.

5. Send the rest of your family to the gatherings with your family but stay home and pamper yourself. Sometimes you and your family can enjoy a break from each other. It doesn't have to mean you don't love each other or you appreciate each other less.

6. Create a "surrogate family" of friends who are as nurturing and supportive as you would like your family to be.
Options:

1. Print some communications hints on a tee shirt that you wear to family gatherings -- things like "get my attention first" and "tell me when you change the subject" and "look at me when you talk to me." Make a game out of it and praise people when they do things right.

2. Help your family understand that other deafened people and their families have the same problems communicating by taking them to ALDA events.

3. Give your family members more insight on what it's like to be deaf by taking them to a silent supper or some place where everyone communicates without using voices.

4. Paper the walls of the place your family is gathering with flip chart paper and have marking pens available all over the place. Keep pads everywhere. Make it easy for someone to write things down if you get tired or stuck while speech reading.

5. Teach your family a song or hymn and perform it together. Select one that's repetitive and easy, like "Happy Birthday to You" or "Silent Night."

6. Get the whole family's co-operation to decide on a signal you can use when you're too tired to follow conversation and need to take a break to recover your energy.

7. Ask for a big family meeting and tell them what you need -- strong light, no glare from windows, clear speech, etc.

8. Buy a bunch of "I Love You" or smiley face stickers and reward family members every time they do something that helps you communicate better.

9. Talk with your partner, kids, or other family members to enlist their help in your grand communication experiment -- make them your allies.

10. Try using Assistive Listening Devices. Don't be shy about putting the microphone constantly in front of people or asking them to clip it to their clothing.
DEAFNESS IN THE CHURCH

Rev. Jan Gronborg Eriksen

My job back in Denmark is as a minister in the Lutheran Church of Denmark. The Lutheran Church of Denmark is one church for 90% of Denmark's population of 5 1/2 million people. While we do have some religious minority groups, having one church makes it very easy for us when it comes to meeting special needs because the church is so large.

What I would like to do here is raise some questions:

1. Why are the questions about God and religion relevant for late-deafened adults?
2. What makes late-deafened adults special to the churches?
3. What do churches in Europe do, and what are your wishes here in America?

When you suffer a serious loss, when life goes against you, it's natural to feel anger. But where do you direct that anger? If you were brought up as a religious person, it's natural to be angry with the Creator, because it is He who failed His promises. This can be compared to the relationship that teenagers have with their parents. Some parents actually fail, seriously fail, their responsibility. But we all, to one extent or another, fail our promises that we make to our children when they are small stating that as long as they are with us, nothing bad will happen. We fail. Sometimes our children can become very, very angry with us as a result. This anger toward the parents, may be expressed as a disconnection.

That is an issue for the psychologists. My issue, as a minister, is to claim that the same thing may happen with the anger that we may have against our Creator; being angry with God when life really doesn't turn out as we expected, may also result in feelings of disconnection. You say, "I will have nothing to do with Him. There is no God." So you may react by disconnecting from God and by disconnecting from religion and spirituality. This is not a rare reaction.

Another reaction may be to express your anger in prayer such as we see in the Old Testament, in the lamentations against God in the Bible's book of Job. Or in the Psalms of David. He is not soft either. When he's angry, he's really angry.

We were not brought up like those old testament guys. The prayers that we learned in our childhood were of another kind. We learned to say "Thank you." And we learned to say, "I pray for this and that. And if I pray enough and believe enough, God will make it
happen." That is what we learned. That is what I learned as a child; but I cannot use that kind of prayer for anything when life breaks down. That is when I need pastoral counseling.

Imagine the difference between yelling like the Old Testament giants into the night, "God, I hate you!" -- or, the more normal way, silently closing the door to the deep part of yourself that used to contain your religious life. What a difference!

A Danish Jewish rabbi said, "I think we Jews are more closely related to God." He said that with a smile. "Because," he said, "I chat with him all the time. Like with my wife. When I'm happy, I thank Him; when I'm confused, I ask advice; when I'm unhappy, I cry at His shoulders; when I'm in a bad mood, I nag at Him; and when I'm despaired and angry, I pour it out at Him. He's always near me, wherever I am in life. Like any relationship of love, it has many colors. But you Christians," he said, "seem to have a more restricted access to God. It's like you don't show Him all your feelings. How come?"

I must admit that he was right. In our tradition, we dare not use prayer to express all kind of feelings. But if we're angry with God, for instance, for losing hearing, then what can we do? Do we blame ourselves? Or do we turn our back on religion? And if we turn our back on religion, does that not mean that we cut ourselves off from some of the deep layers in our life?

Are we ready to accept that?

Angry or not, the relationship that you may have had with God before becoming deaf -- that is, a relationship between the person you were as a hearing person, and the God that you had been told about -- may be affected.

When your identity gets into a crisis, which normally happens when a person loses their hearing, then the relationship with God also gets in crisis. As a part of your search for a new identity, you will have to search for a new relationship with God, too. Because losing your hearing is a change of the foundation of life.

Language is such an important part of the foundation on which we build our identity, that most deafened people tell me that they are not the same person after becoming deaf. That is a crisis, of course. I know that when they lose their hearing, during that crisis, some people begin to lose respect for themselves, and think less of themselves as a person. Then it will be natural, at least for a religious person, to feel much frustration against the God who they have always seen as an Almighty Loving Father.

Is He almighty at all?

I would say no. That is what I've come to -- I must say no, He is not almighty. For one thing: Who controls me? Who controls what I do to others? Does He?
I'm sorry, I won't let Him. I won't. If I would, everyone around me would be happy. So if He does not control me, who believes in Him, and who wants to serve Him, then why should I believe that He controls everything that happens to me?

Do you see where I'm at?

Well, we do not have the time to discuss it here, but that is the answer that I've come to. You must find your own answers -- and please don't stop searching for them. I feel that as a child in Sunday school, I was lied to. Because I learned that if you believe enough, and if you pray and so on and so on, you will prosper. God will take care of you. He can do anything He wants to. But after living 47 years, I must say, my experience tells me something different from what I heard in Sunday school. So what am I to believe? What someone told me, or what I experienced? This is a difficult question, but I must say like the Jewish rabbi: God promised to go side by side with us, hold our hands, even through the valley of death. He did NOT promise that we should not go through the valley of death. But He promised to be with us. He did NOT promise to solve all our problems, but to share them. Those are very big differences.

People who have experienced severe losses, often experience that there is a conflict between what we heard, and what we see. How do we get through that conflict in our lives? How do we live with the fact that life is not fair? Life is not fair. Life isn't unfair, either. Life simply is, and we are in it. And God is with us.

It's very, very difficult to struggle with these questions alone. I intend here more to raise questions than to answer them. We would not come up with the same answers anyway, for my answers are my answers, and your answers are yours.

I bring up these questions to demonstrate the need that I feel there is for churches to take seriously their responsibility towards hard of hearing and late-deafened persons. As severely hard of hearing or late-deafened, you will have to struggle with these questions, or you will have to give up the religious side of your life.

If you take up the difficult challenge to establish a new relationship between your new identity as a late-deafened person, and the God that you have actually experienced, you definitely could do with some help! This brings us to the question: are the clergy of our churches capable of being partners with the late-deafened in this process? Can the ministers be partners with you in that struggle, in this search, without knowing what it is like to be deafened or severely hard of hearing?

Seen from the point of view of churches, you could say it's a question of accessibility: to make the services of the churches accessible to people with hearing loss. If the ministers know nothing about your life situation, they are not likely to be of much help to you. Accessibility is an important issue for churches. It should be, and it is, but here is also a
very long tradition of there being a difference between what the church is doing and what the church is saying.

We know if you want to treat everybody equally well, you must treat them differently, and you must speak to them differently. Speak the language that they speak, and know some of the background that they have. That is true when you go to preach, and that is true when you go to counseling.

But where are the ministers in this challenge, what are they doing?

Often, psychologists offer unsatisfactory treatment to late-deafened and hard of hearing individuals, because they know too little about the problem of hearing loss. Their intent is good, but their knowledge is insufficient. That is definitely also true for ministers and priests.

There are many examples of clergy who don't even try. My worst examples concern the elderly late-deafened; the people who lose their hearing as old persons. They may not even know the word "late-deafened." They are just old and cannot hear anymore and cannot do very much else anymore, so they have given up on themselves. Often, their ministers give up on them too, and nod at them, and smile at them, and pat their head and go on to the next one.

I go and see people like that when I find them, and very often the occasions when I'm with them are the only occasions where these people actually have a conversation, which may be only four times a year. You have to write everything in this situation. Every word of your side of the conversation you have to write. Most people can write "What time do you want to get up?" or "Would you like cream in your coffee?" But by a conversation, I mean a real one? Who will bother to do that? Apparently very few.

So, isolated as they are, these people go nuts. I can't blame them. Meanwhile, the churches ignore them. So one thing I try to do, of course, is to notify the local ministers about the existence of persons in their parish like that, and say: "This person is not demented, not yet, but he probably will be if you keep on treating him like that."

This is a group of persons that I care for a lot, because they seem to be forgotten by most people. Our organizations rarely meet these people, because those with the problem too often don't have the energy, the motivation, nor the knowledge as to how to contact us.

In some European countries the churches have had, for some decades, special ministries for hard of hearing and late-deafened persons. Of course, we also have had ministers for the Deaf, the culturally Deaf. You've had that too in America for 100 years or so; special congregations for the Deaf. That's a good thing, and they work very well within their special cultural surroundings. But they are of little help for many late-deafened. Some young late-deafened adults more or less immigrate into the world of the culturally Deaf and their
churches. That's good. But it means that we normally lose a lot of people. Namely, most of the severely hard of hearing and late-deafened adults.

To solve this problem in Denmark, we have ministries that have two tracks. First, we have specially educated ministers to offer pastoral counseling to late-deafened people, and to hold worship services that are captioned. We do that regularly in many cities.

Beside that special service, we also have a large variety of initiatives to ease the integration of those who want to be integrated into their local congregations. In my own country, Denmark, we have two special ministers for the hard of hearing and late-deafened. I'm one of them. But we also have working for us, seventy-five local ministers, part-time. We call them contact ministers. They have their parish, and then they do part-time work for us. We train them, so that they can be the person in the local area who knows more than others about serving persons who are hard of hearing and late-deafened. They try to spread that knowledge and attention to all of their colleagues. The system works rather well because there are many contact ministers; seventy-five out of some two thousand ministers in the Church of Denmark.

In that way we reach almost all ministers with the message that there are some people in your parish that you ought to pay attention to, who you ought to know something about, and who you may underestimate. I've found that late-deafened persons and hard of hearing persons are very, very often mentally underestimated by others. That is terrible. That's a terrible sin to do to another person!

In addition we have special captioned worship services, retreats, and a lot of personal counseling. We encourage the hard of hearing and late-deafened persons that we meet, to go to their local ministers and express their needs; because we know that the hard of hearing and very many of the late-deafened too, have a strong will to remain part of their local community, and do not want to be pulled out and put into a special congregation for persons with special needs. They say: "This is my family, this is my village, these are my friends, this is my congregation." Therefore we encourage them to express their needs, to wave the flag where they are. Through our local contact ministers, we meet the parish ministers, and try to inform them about the existence of these people and their needs.

Now I would like to tell you about our international federation, because this line of work exists in some countries -- although still far too few. It is mainly in Germany that they have a very strong tradition of paying attention to the hard of hearing and late-deafened, but it has spread to Denmark, and, to some degree Norway, Sweden, Holland, Poland, Hungary, and Switzerland.

We have for many years tried to write letters to church leaders in the United Kingdom and in the United States, but nobody there ever answered our letters. We have international conferences every two years, and we have wanted to meet people from English speaking
countries. But they seem to have the attitude that they have ministers for the Deaf, so what's the problem?

That attitude, of course, we know from many other places. Our international federation is called IVSS. This organization was born in Germany, and while German is the first language, we have two official languages, German and English. Our headquarters is in Germany.

Through this international corporation, we can see how things are different from country to country. Especially the attitude towards the late-deafened. In some countries the ministers for the Deaf say: "Don't worry about the late-deafened, we take care of them." And sometimes they render a good service to the late-deafened -- but only to those late-deafened who actually learn sign. That leaves out many late-deafened adults, especially the older ones. There is also trouble because in some places, such as Norway, they put the whole emphasis on assistive listening devices. This helps many people, of course, as it does in Denmark too. But until now the churches in Norway and Sweden have said the late-deafened, who may not use assistive listening devices, must be the concern of a congregation for Deaf members. That is the way they want to do it.

In Denmark we would not do like that. Nor in Germany, because we can see how many late-deafened adults will not be able to fit into the congregations of Deaf members. They will not feel at home there. But the attitude varies from country to country, and we discussed these things in our international conferences and learned from each other. Our common goal is that anything that the churches offer should be accessible to all. So our ideal, which we agree on in principle, is that all worship services should be captioned.

We will never reach that goal! We will never get there. But it is realistic to say that in every city there should be regular worship services with captioning service. That is not unrealistic. That's what we have in Denmark, and many places in Germany now. It makes it possible for late-deafened members to have regular opportunities to take part in worship services on equal terms.

Now -- how about the United States? What do you want from your churches here in America? What are your wishes? Do you want like they have in Germany, special congregations for late-deafened and severely hard of hearing? Probably not. For while in some cities in Germany they do have them, in most countries we don't want them to be special and isolated. Still that's one possibility.

Do you want late-deafened adults to belong in the congregations for Deaf members, with the price that some late-deafened who cannot sign are left behind? Do you want special education so that more about hearing loss is known, so that when someone late-deafened walks up to your minister and says, "Hey, I am so and so, and I have a problem," he would already know something about late-deafness?
Would you wish that, for instance, that major towns would have at least one church which has regularly captioned worship services? Maybe not all churches in America can render the services you might need, but at least one church in your town should offer the possibility for you to be part of its worship. If that is what you wish, you could walk up to the minister and say: "Listen, I would like the worship at this church to be captioned so that I can be part of it." He would probably say, "What do you mean? What is that?" You could tell him about it, and then he would say, "How much does it cost?" and you could tell him that captioning service in the United States is terribly cheap. And they can say: "Well, well, well, we have many costs," and so on. Then you can take your wallet up and say, "I'm ready to pay the ticket. How much must I pay to hear the gospel?"

If the minister then says, "Well, that would be $80," -- then it's time to leave and say, "I'll find another church."

I say this because we all know that the church probably has some kind of support program for mission work in Africa -- so that Africans can hear the gospel. They are willing to pay for Africans to be able to hear the gospel in Swahili. How much are they willing to pay for you to be able to hear the gospel? That is a relevant question, isn't it? It is probably even cheaper for them to enable you to hear it.

But if you have to argue with him about it, go somewhere else. If he doesn't understand it when you say it like this, go somewhere else. Someone will understand. And they should. The very large number of ministers, and others from the churches, dealing with hard of hearing and late-deafened members in European countries, has been developed over many years, and it did not come out of the "good heart" of the churches. They are the result of the organizations for the hard of hearing and late-deafened who kept knocking on the doors of the church.

Nothing comes from nothing. If you want to be taken seriously you must knock on some doors. What has to be done in America, I wouldn't know; but our international federation would like to be in a dialogue with Americans. We have international conferences, and we would like to see representatives from the United States there to join in a dialogue with Europeans on how churches can meet the needs of the hard of hearing and late-deafened population. The IVSS is not a mission organization. Our issue is accessibility. We want to give late-deafened and hard of hearing people the same opportunities as other church members.

It would be great to have Americans with us at our next conference, which is in Berlin, Germany next year. Maybe you would, by attending, be somewhat inspired by European initiatives. Definitely we would be inspired by meeting you, I know that. Of course I know that you will never imitate anything that we are doing in Europe, and you shouldn't. Because you Americans - America is different. Yes, I know that you think Europe is different. But it's not. It's you who are different!
But the dialogue would be a very great inspiration. So maybe some of you would join the IVSS as personal members.* That's only $6 a year, just symbolic. Being a member of the organization would be a signal to the churches where you come from that there is a task to be taken seriously. What we want the most is for organizations and churches to be members; not just simply to increase our membership numbers, but as a sign that these challenges are taken seriously and solutions sought.

I'd say to each of you: If God used to be important to you when you were hearing, don't give Him up. Please, don't give up on the churches, either, because they are supposed to be the Body of Christ, and He is our Brother.

He is your Brother too.

* Membership applications should be sent to:
  IVSS
  Krokusstrasse 1,
  D-48527 Nordhorn, Germany.
  Fax: +49 5921 777 02

  Jan Gronborg Eriksen
  Kancellivej 5,
  DK-5200 Odense V, Denmark.
"Never doubt that a small group of thoughtful, committed citizens can change the world; indeed it's the only thing that ever has." -Margaret Mead

When the Thermos Corporation wanted to make the best possible outdoor barbecue grill, the company's marketing division turned to their customers for advice. They proceeded to establish focus groups in which they asked consumers what features they wanted most in "the ideal grill." Thermos surveyors and design engineers worked together in assessing the opinions of consumers and converted those ideas into the grill people said they wanted. The grill was a huge success.

With this example of consumer input as an analogy, the staff of the Rehabilitation Research and Training Center on Mental Health for Persons who are Hard of Hearing or Late-Deafened (RRTC), at the California School of Professional Psychology, San Diego, California, has coordinated a series of focus groups with late-deafened adults, and their family members. Questions posed during these groups attempted to get to the heart of significant issues related to hearing loss which strikes in adulthood such as the impact on personal adjustment, employment barriers, communication issues, family dynamics and social factors.

This report will outline the process of the focus group study and provide readers with the significant findings of that process. Recommendations and suggestions regarding future research, and a model service delivery system developed with consumer input will be outlined.

Methodology

Many of the participants for the focus groups were referred by local agencies serving late-deafened adults. Coordinators, who were late-deafened themselves, were also responsible for the recruitment of participants and for leading the focus group at each site. The coordinators included such notables as Lara Shepard, San Diego; Mary Clark, Chicago; Steve Larew, Rockford, Illinois and San Francisco; Judy (Tingley) Viera, Madison, Wisconsin; Edna Shipley-Conner, Oakland, and Fremont California; Cheryl Heppner and Robin Titterington, Fairfax, Virginia.

T. Jordon Goulder, Associate Director of the RRTC, served as the leader of the group sessions which were composed of family members and significant others. The input from
these groups provided the researchers with information on how the hearing loss of their partners and friends has affected their relationships with the individual, as well as the family system. The premise that communication is a "two-way-street" provided the impetus for interviewing the family and friends of people who have experienced late-deafness.

Late-deafened participants and family members were asked to fill out information questionnaires prior to attending the focus group. These questionnaires varied slightly in order to obtain information from perspectives of the person with hearing loss and from significant others. Each group of deafened individuals consisted of eight to ten members who met for approximately two hours. Family groups varied in size from three to ten persons, and met for the same two hour period. All groups with participants who were late-deafened were provided with Computer Assisted Real Time Captioning (CART), and all sessions were videotaped for future analysis.

During the sessions late-deafened adults were asked to respond to eight questions that were developed through a process originally developed for focus groups for persons who are hard of hearing. These questions were then reviewed and edited by members of the Executive Board of the Association of Late-Deafened Adults (ALDA). Reviewers included, Cheryl Heppner, Robin Titterington, Mary Clark and Steve Larew. The comments of reviewers were then evaluated by project staff and where appropriate, incorporated into eight final questions.

The questions for family members and significant others were similarly developed with feedback from people who are late-deafened as well as input from family members and RRTC staff. The questions were designed to elicit information regarding the family member's adjustment to the challenges of late deafness.

The verbatim record of each participant's comments was entered into a data base which allowed the staff to analyze both individual and group profiles. This permitted the researchers to record comments and then cluster these comments into profiles based on factors such as age, gender, marital status, age of onset, and duration of hearing loss, education, and employment. (See Appendix A for statistical profiles.)

Focus Groups Begin

A total of 127 people participated in 17 focus groups; 93 late-deafened adults participated in 12 focus groups; and, 34 people participated in five groups for family members and significant others. These focus groups were designed to allow participants to express their opinions on selected topics and concerns in a confidential and safe atmosphere.

Individual responses to each of the eight questions were recorded via the CART reporter. Transcripts of the group's comments were then analyzed by RRTC staff looking for a pattern that was duplicated by other participants in each of the 17 groups. After identifying recurring issues made by participants, the statements were organized and labeled to reflect
The themes. The labels given to each cluster were then referred to as a "topic of concern." Recurring themes evolved into nine topics: Understanding Hearing Loss; Implications of Hearing Loss for the Individual, Spouse, Family; Coping Skills for the Individual; Coping Skills for the Spouse/Significant Other/Family; Communications Strategies; Assistive Devices and Technology; Americans with Disabilities Act (ADA) - Employment Issues and Beyond; Resources, Strategies and Support Groups (Local and National); and On-line Services.

The nine topics were then put into a questionnaire that was mailed to all persons who had participated in the focus groups. Participants were asked to rank order their preferences from the list of topics to be presented at future training sessions identified as Family Institutes for Late-Deafened Adults. The responses to this questionnaire were then classified according to age, gender, and duration of hearing loss.

After reviewing information obtained from the first questionnaire a second short form questionnaire was developed to gain additional information. Added items were concerned with the following: use of medication or drugs as a coping technique, increased use of alcohol as a result of hearing loss, additional communication methods used, recipient of SSI or SSDI, religion or spiritual experience as a coping mechanism.

Demographics of the Participants and Gender Implications

Nearly three-quarters of focus group participants in this study were women. The large proportion of female participants raises several interesting questions that could be a focus of future research and encourage outreach toward case finding efforts directed at men who are late-deafened. The large female participation in the focus groups also may reflect the current membership in ALDA, Inc., which is predominately women. Are there more women than men who are late-deafened? How are the adjustment needs of men different than woman who become deafened? How can we better our outreach efforts to reach men who have lost their hearing? All of these are important questions that need to be explored.

The age of the individuals represented in the focus groups provided a diversity of personal viewpoints regarding adjustment to deafness. These diverse views and adjustment differences were even more pronounced when the age of the participant interacted with gender. For example, deafened women who were married and had school-age children were confronted with a unique set of problems. They indicated that they not only had to contend with a spouse who was hearing and adjust their marital relationship, but they were also challenged with caring for and communicating with their children who ranged in age from preschooler to high school students.

In one particular focus group there were three women who had become deafened and all had children still in elementary school. These women expressed frustration and concern for their children's educational development and the mother-child relationship in terms of their own deafness. They raised several important issues which included: shame their
children might feel towards them being "different;" the children's reactions when mom just plain can't hear or understand them; the frustration with teaching their kids different ways of communicating with them versus running to dad for permission because communication is easier with him; and the difficulty they felt with communicating with new people such as their child's teacher.

The issues raised by mothers with young children were different from those who had teenagers or adult children. They reported with frustration the notion that older children were more fixed in their communication patterns with them and tended to have less inclination and time to learn new methods and strategies for improved communication.

Family structures added another variable in that 25% of the participants were divorced. Women who were divorced, deafened and functioning as a single parent portrayed the most stressful lifestyle in coping with their hearing loss. They were pressured by lack of funds, employment concerns and general household management.

Participants who were deafened in early adulthood and in the pre-career stage, expressed the most concern about loss of social relationships, how to obtain advanced education, and/or find appropriate employment. Participants who were deafened before the Rehabilitation Act of 1973, indicated that their choices of post secondary education were limited to the prevailing options for students who were primarily prelingually deaf which included Gallaudet University, The National Technical Institute for the Deaf, and several smaller community college and university programs designed for students whose preferred mode of communication was sign language. There was little support for students who had become deaf and used alternative modes of receptive communication in the classroom such as oral interpreters, cued speech, and note taking.

Participants who were in the mid-life age groups expressed concern over work issues such as limited advancement opportunities, job performance, retention, and possible job loss due to their deafness.

Those participants who were 60 years of age and over had less formal schooling than those who were younger and were less concerned with employment issues. They were more focused on retirement plans, isolation and dissociation from family and friends related to their hearing loss.

**Hearing Loss Level**

While the majority of persons attending the focus groups self-identified as profoundly hearing impaired (66%), it is interesting to note that 6% identified themselves as experiencing a moderate loss and 17% identified themselves as having a severe loss. More than 80% of focus group participants were also ALDA members. This finding raises the question of who joins groups like ALDA and why? Obviously, not only people with a profound loss of hearing join ALDA.
People who participated in the focus groups discussed their alliance with ALDA, as well as their reasons for joining. Some ALDA members reported that they joined because "this group is younger in age than some of the Self Help for Persons who are Hard of Hearing (SHHH) groups." Others, with moderate hearing loss, were members before having surgery for a cochlear implant. These members continue to find refuge and understanding in the ALDA social setting, and now represent a growing proportion of the ALDA membership. In a review of focus group participants, 14 were identified as having a cochlear implant.

Other factors influencing attendance at ALDA functions include the use of technology during meetings, and the unrestricted freedom of communication styles. When CART is used on a regular basis for ALDA meetings, persons who are hard of hearing or Deaf reported that they participate in meetings because of the easy access to information. Another consideration was the degree of comfort members felt with having the ability to communicate in any mode or style they preferred during meetings. Methods used included: receptive speech reading; note writing; sign language; CART service; expressive speech; and combinations of methods using all of the above.

**Employment and Education**

Approximately half of the participants interviewed were employed either full time, part time or self-employed. These participants also had a higher level of education than the general population. While no data was collected on types of employment, or income levels, a number of the participants were in professional roles such as lawyers, nurses, teachers, and counselors.

Issues of technological assistance on the job were discussed by the participants with major concerns identified as: the use of the telephone, relationships with supervisors, and general communication issues with other employees. High educational levels and years of experience in the work place prior to becoming deafened appear to provide participants with more job security by self-report in contrast to younger deafened individuals who are faced with training issues and lack of job experience. However, even the well educated and experienced workers expressed frustration regarding employment mobility and retraining in the work place.

**Onset of Hearing Loss**

Gradual hearing loss in this report refers to people who have some type of hearing loss which increased over time. Individuals who are diagnosed with some form of progressive hearing loss may or may not become deafened. People with gradual hearing loss reported that many adjustments they made as their hearing loss progressed went unnoticed by family and friends. Some people stated that, "It would be easier just to say, I'm deaf," than to contend with misconceptions of their hearing ability.
For those who experienced a sudden hearing loss, their age, gender, life situations and their disposition prior to hearing loss, all appear to be major factors in how they respond and adjust to their deafness. For example, persons who experienced a sudden hearing loss in ages 18-29 expressed concerns about their restricted choices of education, loss of social companions, and securing and maintaining employment when they did not have many years of work experience. Persons ages 30-39 were a critical age group for married women with children and women who were single parents. Questions such as "How do I raise children who have known me as a hearing mother and are now faced with a mom who has 'broken ears'?

The largest number of persons in this study (52) was in the 40-59 age group. Gender, employment, age of children and lifestyle were all seen as factors which contribute to, or complicate their adjustment to deafness. Married couples without children reported being most concerned with relationship adjustment. Married couples with children talked about marital adjustment, child rearing, employment questions, and socialization issues. When the male partner was deafened, employment and marital adjustment were the two major issues discussed.

The ages 60-plus group represented a unique set of issues with a bigger proportion living alone, either because of divorce or the death of a spouse. More persons were retired and had adult children. The adult children of the 60-plus year old group who were interviewed were concerned with their parent's welfare and socialization needs, but reported little knowledge of how to communicate with their deafened parent and/or the proper use of assistive devices which might improve communication.

**Communication Methods**

People who are late-deafened in this study predominately relied on speech as their primary mode of expressive language. The use of sign language as a mode of expressive and receptive language appears to be related to a set of variables such as age of onset of deafness, the point in time at which the individual became deafened, i.e., being deafened in 1975 is a very different experience from being deafened in 1995, with a seemingly wider acceptance of various modes of communication including sign language and technological advances coming in later years. The vocational status of the deafened individual, gender, and technological awareness of the individual also appear to be factors in communication modes used by people who become deaf.

The issue of acceptance in the Deaf Community was brought up in most focus groups. People who were deafened tended to report feelings of rejection by people who were born deaf and grew up with Deaf Culture. This rejection was assumed to be partly due to the deafened person's inability to communicate in American Sign Language. Respondents perceived themselves being unfairly judged by their inability to use American Sign Language.
The study of group communication for persons who are deafened is still to be explored. However, direct communication for deafened persons was made possible in the focus groups by the use of CART services for group communication. The average cost for this support service was $85.00 per hour for a total of $2,500 to provide this service for the focus groups. The relationship between technology and late-deafened persons needs to be explored.

Use of Hearing Aids

Hearing aid use among participants was primarily by people who self-reported that they were moderately to severely deafened. Aids were used by 52 participants. Participants who were profoundly deaf in this study reported little or no benefit from hearing aids or assistive listening systems.

Some participants related in the sessions their experience of being hard of hearing and then becoming deaf. They suggested that the length of time that they were hard of hearing was an important factor in adjustment to their subsequent deafness. People in the focus groups who had a fairly rapid or sudden hearing loss expressed the most difficulty in adjusting to their deafness.

Other participants described how they had been hard of hearing, then deafened, and then had a cochlear implants and became hard of hearing again. In most of the 14 cochlear implant cases reported, the cochlear implant recipient reported that auditory levels had improved and they were able to resume functional use of the telephone and they experienced a greater increase in speech recognition. Psychological recipients described the transient world of their pre- and post-implant identity as difficult for them. Further complications arose with how the changes taking place in their functioning were misunderstood by optimistic expectations held by spouses, children and fellow employees. The overly optimistic expectations following an implant implied that, "You are hearing now." Such extreme views tended to complicate the readjustment of the cochlear implant recipient.

Summary of Findings

The number one concern that was reiterated by both individuals who were late-deafened, and family members interviewed was related to communication difficulties; at home; in the workplace; and with friends and other family members. Other top concerns of people who are late-deafened in these focus groups included: dealing with depression and withdrawal; learning coping skills; finding information out about deafness; staying positive; socializing; issues of independence; and intimacy.

Family members interviewed had many similar issues besides communication difficulties which included: understanding deafness; keeping informed about technology - what it can
50 Results of a Focus Group Study

and cannot do; dependency and co-dependency; relationship and intimacy issues; and emotional support for family members too.

These important concerns, summarized above, that the 127 individuals so willingly shared during the focus groups over the past year will be incorporated into the recommendations and training proposed to accompany these findings. Follow through on the recommendations will provide the impetus for changing the current state of inadequate services to meet the intense needs of families when one person in it becomes deaf.

Conclusion

The recommendations made in this report are the result of input from late-deafened adults, their family members, and the experience of the RRTC staff. The proposed Individual and Family Life Center for Late-Deafened Adults would be a research-based center that would serve a regional area of the country. The initial Center would conduct research and provide training in the area of late-deafness, and support the development of a regional system of Individual and Family Life Centers.

The concept of Regional Centers to assist persons who are deaf-blind has a successful track record of this type of service. The Helen Keller National Center has regional offices in the ten federal regions of the United States. They also have a technical support system under a separate grant which serves the regional offices. It is this model of case finding, intervention, technology and support that the RRTC San Diego is suggesting as the model for persons who are late-deafened.

It is the hope of all those who have conducted this research project that the vision for this type of model Center will become a reality in each of the 10 Federal regions of the United States.

As the author of this report, I want to thank all the late-deafened persons and their family members who have contributed their time and effort to attend the Focus Groups. It is my sincere hope that the common vision of all who have participated will result in new and expanded knowledge and service for late-deafened adults and their families.

As a group, late-deafened people are open to all ways of knowing and communicating. In honor of their words about themselves the following statements and paraphrases are written here with the hope that these shadowy words will cast a reflection on the real image of who late-deafened people are and what they want.
General Comments

"My community affiliation is the hearing world."

"My internal sense of identity is somewhere between two worlds, the person I am now, and the person I used to be."

"People who have known me when I was hearing still think of me as hearing."

"I want to see visuals, I especially love captions on T.V. and Real Time Captioning."

"Some of us are diagnosis able. We have a form of Post Traumatic Stress Disorder, we keep thinking of the event that caused our hearing loss, and can't stop repeating the story."

Relationships

"My greatest struggle is with my husband."

"My greatest struggle is with my wife."

"I've made such effort to communicate, what about my family trying to communicate with me?"

"I worry about being a mother. My kids are young and run to their father for everything."

"My social life has changed a lot. I like being with late-deafened people most."

"My neighbors try to talk with me. But we just don't have the same relationship."

"Sports are good for making and keeping friends."

Employment

"I worry about my job. Can I keep up when I can't hear?"

"My boss has tried to help me. They gave me a TTY, but it's hard to communicate when you can't use the regular phone."

"I am a professional but I still bluff my way around the office. I have someone fill me in on important discussions."

"I worry about keeping my job now that I am deafened. My hearing aids use to help me but now I'm lost."
"I get so tired explaining what is wrong with me."

Social Life

"I love going to ALDA meetings."

"It's so hard to be at a social function and to try and have a conversation."

"I only go if I have too."

"I go to foreign films now."

"I live for the AldaCon."

"If I could only hear the music again."
Appendix A

Results of Focus Groups to Late-Deafened Individuals
and Their Families and Friends

To date there have been 17 focus groups conducted throughout the United States with 126 total participants.

Specific data on the Late-Deafened Participants:

*Some participants did not respond to every question or did not complete or return their responses.

<table>
<thead>
<tr>
<th><strong>Employment</strong></th>
<th><strong>Living Arrangements</strong></th>
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<tbody>
<tr>
<td>49% are employed (either full/part time or self employed)</td>
<td>18% Widowed</td>
</tr>
<tr>
<td>26% are retired</td>
<td>14% Single</td>
</tr>
<tr>
<td>14% are unemployed</td>
<td>3% Significant Other</td>
</tr>
<tr>
<td>6% are homemakers</td>
<td></td>
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<tr>
<td>6% are students</td>
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<thead>
<tr>
<th><strong>Ethnicity</strong></th>
<th><strong>Use of Religion as Coping Technique</strong></th>
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<tbody>
<tr>
<td>78% Anglo; white</td>
<td>66% Yes</td>
</tr>
<tr>
<td>9% Hispanic</td>
<td>33% No</td>
</tr>
<tr>
<td>6% Other</td>
<td></td>
</tr>
<tr>
<td>3% African American</td>
<td></td>
</tr>
<tr>
<td>2% Native American</td>
<td></td>
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<tr>
<td>2% Asian American</td>
<td></td>
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<thead>
<tr>
<th><strong>Gender</strong></th>
<th><strong>Increased Use of Alcohol/OTC Medication as a Result of Hearing Loss</strong></th>
</tr>
</thead>
<tbody>
<tr>
<td>72% female</td>
<td>17% Yes</td>
</tr>
<tr>
<td>28% male</td>
<td>81% No</td>
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</tbody>
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<table>
<thead>
<tr>
<th><strong>Education</strong></th>
<th><strong>Use of Anti-Depressant Medication</strong></th>
</tr>
</thead>
<tbody>
<tr>
<td>29% College degrees</td>
<td>16% Yes</td>
</tr>
<tr>
<td>27% Some college</td>
<td>84% No</td>
</tr>
<tr>
<td>24% Advanced degree</td>
<td></td>
</tr>
<tr>
<td>8% High School graduate</td>
<td></td>
</tr>
<tr>
<td>8% Trade or Technical School</td>
<td></td>
</tr>
<tr>
<td>3% Did not graduate high school</td>
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<thead>
<tr>
<th><strong>Hearing Loss Level</strong></th>
<th><strong>Location of Late-Deafened Adults</strong></th>
</tr>
</thead>
<tbody>
<tr>
<td>68% Profound</td>
<td>79% Major metropolitan area (+1 million)</td>
</tr>
<tr>
<td>16% Severe</td>
<td>10% Small city (less than 100,000)</td>
</tr>
<tr>
<td>9% No detectable hearing</td>
<td>6% Large city (250,000–999,999)</td>
</tr>
<tr>
<td>7% Moderate</td>
<td>1% Rural area (less than 1,000)</td>
</tr>
<tr>
<td>1% Do not know level of loss</td>
<td></td>
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<thead>
<tr>
<th><strong>Marital Status</strong></th>
<th><strong>Modes of Communication</strong></th>
</tr>
</thead>
<tbody>
<tr>
<td>39% Married</td>
<td>Percentage shows &quot;yes&quot; response</td>
</tr>
<tr>
<td>25% Divorced</td>
<td>63% Speaking and listening</td>
</tr>
<tr>
<td></td>
<td>47% Sign language</td>
</tr>
<tr>
<td></td>
<td>27% Laptop computer</td>
</tr>
<tr>
<td></td>
<td>81% Lip/speech reading</td>
</tr>
<tr>
<td></td>
<td>55% Oral or sign language interpreters</td>
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### Results of a Focus Group Study

<table>
<thead>
<tr>
<th>Other modes of communication</th>
<th>Use of Assistive Technology</th>
</tr>
</thead>
<tbody>
<tr>
<td>36%</td>
<td>Percentage shows &quot;yes&quot; response</td>
</tr>
<tr>
<td>6% Cued Speech</td>
<td>31% 1 Hearing Aid</td>
</tr>
<tr>
<td><strong>Rate of Hearing Loss</strong></td>
<td>30% 2 Hearing Aids</td>
</tr>
<tr>
<td>46% Gradual</td>
<td>16% Cochlear Implant</td>
</tr>
<tr>
<td>32% Sudden</td>
<td>Other Family Members with Hearing Loss</td>
</tr>
<tr>
<td>19% Combination</td>
<td>32% Yes</td>
</tr>
<tr>
<td>2% Don't know</td>
<td>62% No</td>
</tr>
<tr>
<td>1% Born deaf</td>
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MENTAL HEALTH SERVICES FOR ADULTS WHO ARE HARD OF HEARING OR LATE-DEAFENED

Carren Stika

The Rehabilitation Research and Training Center in San Diego has been funded by the federal government to look at the mental health needs of persons who are hard of hearing or late-deafened, and to identify the mental health services available to these two groups of individuals. One project that we conducted was a national survey asking people who are hard of hearing or deaf about their experiences obtaining mental health services. For example, did they go for mental health services? If they did go, why did they go? If they went for mental health services, what were their experiences? Did they feel that the therapist understood their mental health needs, accommodated their communication needs, or helped them deal with their mental health needs, particularly as they related to their hearing loss?

Let us talk a little bit about the results of that questionnaire. The questionnaire was distributed in a variety of ways. One way was through the December 1995 issue of "Hearing Loss," which is the journal published by Self Help for the Hard of Hearing. Another way that we disseminated the questionnaire was through SHHH and ALDA chapter meetings. Also, every time we spoke at various meetings, we asked people to complete the questionnaire. Finally, the questionnaire was mailed to all ALDA national members. A total of 970 people completed the questionnaire. We received questionnaires from all over the United States. Every state was represented, except two. We also received completed questionnaires from foreign countries — one from Chile, several from Canada, some from Europe.

We found those completing the questionnaire varied in age, but most of the people completing the questionnaire were older than 60 years. That's going to affect the results of the questionnaire. The level of hearing loss among respondents varied. Most people reported that their hearing loss was in the severe or profound ranges, but some of them, 25 to be exact — reported that their hearing loss was either moderate or mild.

About two times as many women as men completed the questionnaire. That's not surprising. Sometimes women are more interested, it seems, in mental health services or issues than men are, or more are willing to admit to it.

Among respondents, the onset of hearing loss occurred equally across age ranges. In fact, two thirds of people responding reported that their hearing loss had occurred before the age of 40. Maybe their hearing loss had not been officially diagnosed, but when they look
back, they realize that it began much earlier. This supports other research that has been done, indicating that the onset of hearing loss probably occurs much earlier than we expect. And that has significant implications for mental health services. Hearing loss does not only occur with people over age 65, 70, or 80, but it occurs much, much earlier, and it is important for people who provide mental health services to know the age of onset.

Most respondents reported that their hearing loss occurred gradually rather than suddenly. Again, remember the people completing this questionnaire included both late-deafened and hard of hearing individuals. Respondents who identified themselves as late-deafened often reported that their hearing loss began suddenly, whereas respondents who identified themselves as hard of hearing often said that their hearing loss occurred gradually.

A surprising number of people responding indicated that they had had a cochlear implant. We say "surprising" because we were not expecting that. We were happy to see it. It tells us that this group is becoming larger and larger, and that we need to consider their unique mental health needs because those needs are likely to be different from the needs of people who are hard of hearing, or those who are deafened but do not have a cochlear implant.

The majority of respondents were white with 50% married, 15% widowed, 16% single, and 12% divorced. I tell you these numbers because, when you do research, you have to be thinking about the people who respond to your questions. If you have one group only, and you are not including another group, then that's going to affect the results that you obtain, and how much you can generalize to the overall population of people.

In addition to receiving answers to specific questions in our questionnaire, we received over 1,500 written comments from people. Some comments consist of simply one or two words, while others were two or three pages long. People really responded to the questions that we asked, and we found their additional written comments to be particularly helpful in understanding their needs and concerns.

When we asked people, "Have you gone for mental health services?" one third of the people said yes. We also found that the people who had more severe hearing loss reported going to mental health services more than the people who had mild hearing loss. Of the people with profound hearing loss, 42% reported seeking mental health services. We also found -- and this is not surprising -- that age was related to seeking mental health services. Younger people were more apt to seek mental health services than older people.

One of the questions asked was: "Did you encounter any difficulties obtaining or locating someone who understands hearing loss and issues related to hearing loss?" About half said yes, they had difficulty finding someone. Most people said they went for mental health services for reasons not related to the hearing loss. That should not surprise us. Most people who have hearing loss are people with life experiences like anyone else's. They have experiences with divorce. They have experiences with deaths of parents. They have
problems with their children. Their life experiences are not only limited to their hearing loss. So when people go for mental health services, they're not only seeking services to help them deal with their hearing loss, they're going for those services because they are dealing with all the variety of life experiences and struggles that we all do. And that's important for people who are providing services to individuals with hearing loss to remember.

When people are looking for mental health providers, they are not specifically looking for someone who knows something about hearing loss. If they are struggling with divorce, they are looking for a good therapist who knows how to work with people going through divorce. If they are looking for someone who can help them with their child's attention deficit problem, they are not looking for someone who knows something about hearing loss. They are looking for a person who knows how to work with children.

One comment made was:

"I did not even attempt to find a counselor that had experience in this area. Instead, I strove to find the best counselor that I could find, and the one that I was comfortable with."

Here's another comment that suggests that mental health providers don't know how to differentiate between mental health issues and the hearing loss experience.

"The psychiatrist could not differentiate between neurotic defenses and defensive behavior caused by my frustration at not hearing well, especially at parties, professional meetings, et cetera. One doctor, who is now becoming hard of hearing himself, recently admitted to me that he now realizes he was wrong to keep dismissing my complaints on how much I was missing."

Sometimes people who are serving individuals with hearing loss don't make the connection between hearing loss and adjustment problems. For example:

"My counselor could not believe that my hearing loss was a contributing factor. I say loss of hearing makes your feeling of self-esteem or self-worth shaky."

Another comment was:

"They seemed to just learn along with me. I never felt they were aware of the real barriers I dealt with on a daily basis."

It seems that when people with hearing loss go to therapists they find that they have to teach the therapist about the implications of their hearing loss. They are hoping that the
therapist can help them adjust. But, instead, they are teaching the therapist. One person wrote on a questionnaire, "I'm paying the therapist to teach him. He should be paying me!"

The next comment is another one that we saw often enough to suggest that it is a problem faced by individuals with hearing loss when they attempt to obtain services appropriate to their needs:

"My selection was restricted to my insurance company, none available with my HMO."

People with hearing loss are connected, like many of us, to their HMO's. There might be a therapist in their community with expertise in hearing loss, but that person is not a provider in their HMO. Their hospital, or HMO, does not identify hearing loss, or knowledge of hearing loss, as a specialty, and, therefore, refuses to authorize payment for those services. That is becoming a bigger and bigger problem. If someone has a heart problem, and a doctor is not available within that particular hospital to treat that problem, of course that HMO is going to refer the patient out to someone who can provide appropriate services. Why is that not true with hearing loss? It, too, involves expertise.

Another comment reflected the experience of a person who was late-deafened and was referred to a mental health center that claimed to have knowledge in working with individuals who are deaf or hard of hearing.

"I attended Gallaudet University as a hearing graduate student and experienced sudden binaural hearing loss. I was referred to the deaf counselor. She did not understand the problem, since, as she said, 'You know sign language.' I was not culturally deaf, but I was also not functionally hearing."

People assume that when you say, "I am deaf," that, well of course, you know sign language! That is all it takes! Or they refer an individual who is deaf to deaf clubs or to the national organizations for the deaf, not realizing that we are talking about apples and oranges and very significantly different life experiences. Individuals trained to work with the culturally deaf are frequently not trained to work with people who are late-deafened. I can tell you that from my own experience.

Over 90% reported that their therapist was either "very responsive" or "somewhat responsive" to accommodating their communication needs. We were actually somewhat surprised about this finding. However, before we think all is fine out there, let's look at some of the comments.

"Very responsive. She slowed down when I asked her to. She sat close to me and faced me. We arranged things so that the light was on her face."
This therapist knew, when dealing with someone with a hearing loss, that she needed to sit closer, needed to speak slower, and needed to have that person see her face.

Another positive comment -- and we received many:

"My counselor seemed to instinctively sense my need to watch her face at all times. She always speaks directly at me. She does not over-articulate, but looks at me directly. I don't feel that she downgrades me in any way because of my having to work at hearing."

"A very sympathetic, empathic, appropriate recommendation for the individual with a hearing loss."

Here's another one that was very typical:

"I never knew myself what was needed, other than asking people to 'speak up' when I couldn't hear. They forgot so quickly. I joined group therapy, which was even worse! No one acknowledged my hearing loss or even tried to look up, speak up."

What we are seeing here by this comment is that the person with the hearing loss did not know what was needed. So they could not advocate for their own communication needs. All they knew was, "Speak up." Therapists can be sensitive about simple accommodations like sitting closer, speaking more slowly, and having the person be able to watch the lips. But the therapist did not seem to know about the more sophisticated means of accommodating the client with a hearing loss. Some additional comments were:

"At times, he would cover his mouth with his hands and the office was not as lighted as I felt it could be. He wanted ambience!"

"You tell people you have a hearing loss and to speak louder and face you. They do it for a few moments. Then forget the next minute. It's frustrating. I am hard of hearing not deaf - and there is a big difference. I do not know lipreading or sign language. They assume I do."

Now, I don't know how many of you have gone for therapy yourselves, or have seen therapy on movies and television, but the image that comes to mind is of a very dimly lit, very quiet, darkened office with a plush seat. That's the worst lighting arrangement for an individual with a hearing loss! Also, what we are seeing here in this comment, which is typical of the many comments we received, was that the therapist tried, changed initially, and then completely forgot, and the individual with the hearing loss had to keep reminding the therapist to accommodate his or her needs. It's difficult being in a position, as a patient or a client, and having to remind the therapist, to be more sensitive and aware of you. It's a very difficult dynamic.
There are assumptions being made by the mental health professional about a person with hearing loss. One assumption being that anyone with a hearing loss is like Marlee Maitlin in the movies. They assume if you have a hearing loss, you know how to read lips, and you know sign language. That is not true. That may be true for the culturally deaf, the prelingually deaf, but not true for people who are hard of hearing or late-deafened.

More comments were:

"My experience has been that assistive listening devices are not made available to patients who are hard of hearing or are being treated in private hospitals, let alone in psychologists' offices."

This comment reflects another piece of information that we found that even though the majority of people responding to this questionnaire reported having severe to profound hearing losses, the mode of communication that was most often used in therapy was just simply voice. Only 8% indicated using an FM system. Only 11 individuals out of the 970 indicated using direct audio input. Only 8% said they used sign language. Only 2% said they used an interpreter. And only two individuals said they used a CART system. Almost 20% said they relied on paper and pencil to communicate. So what we are finding is, while therapists are willing to make accommodations, like speaking up or talking more slowly, their knowledge of technology that can greatly enhance communication in the therapy room, is very, very limited.

"How satisfied are you with the mental health services you received?" Three-quarters of the respondents said they were either very satisfied or satisfied with the mental health services they received. Now, when we came up with that number, 75% satisfied or very satisfied, we began thinking maybe we didn't understand the situation! Maybe it's actually much better than we think! Well, this is a problem with research. When you ask for numbers, you don't really know what's behind the numbers. And that's why the comments that were provided proved to be very helpful in clarifying the situation for us. Let's look at some more of those comments.

"Satisfied in relation to other issues. Very dissatisfied in relation to dealing with my hearing loss. It was very frustrating to have to keep explaining why my hearing loss gave me problems in other settings, when was told 'but you do so well with me.'"

This comment reflects the common experience of individuals with hearing loss feeling that they have to defend that their hearing loss is indeed affecting their lives! The therapy situation of one-on-one communication is very different from the situation of sitting at a family meal, or a relative gathering, or going to work and being in a group business meeting. It's a very, very different situation. And it appears that mental health professionals typically don't appreciate this.
Here is another comment:

"My counselor could not believe that my hearing loss was a contributing factor to my problems. I say loss of hearing makes your feeling of self-worth shaky."

Again, the therapist appears to be basically saying to the client or patient, "Come on, come on, get out of it, it's not that bad!" And the individual with the hearing loss is saying, "But you don't really understand!" Keep in mind, as previously mentioned, most people go for therapy for reasons that everyone goes to therapy for, not just to deal with their hearing loss. However, if, for example, they are talking about problem relationships with their children and an issue around their hearing loss comes up, such as their child refusing to communicate with them or being embarrassed about them, and the therapist is saying, "It's not such a big thing," that person is not going to feel very understood or helped.

A frequent comment was:

"I felt that there was just too much educating to do and that we are never going to get to the problem."

Again, that feeling expressed that a therapist may know psychology, may know mental health, but not know about life experiences in regard to hearing loss! And these life experiences are related to mental health.

There is just too much educating to do.

Additional comments were:

"It was 20 years ago. My hearing loss was not a big issue at that time. We didn't deal with it. In retrospect, however, I realize that it was one of my issues, if not my main one, and if the counselor had been attuned to that, we might have dealt with the loneliness, struggle to cope, fatigue, depression, and the anxiety I was feeling."

"We never got to the subject. I knew it was a problem, but I had no idea that my depression could stem so profoundly from communication problems! Hearing loss was a physical problem - not mental, even though I knew it affected me emotionally."

What we are seeing here is that the therapist is not making the connections between the mental health issues that the person is reporting and his or her hearing loss. The client is not trained in mental health. They don't know that their mental health experiences are related to their hearing loss. They're hoping that the expert is going to do that work for them. But what happens is that that expert doesn't have the expertise in the area of the
affects of hearing loss on individuals, and, thus, does not make the connection for the person.

To summarize the findings from this questionnaire, what we are finding is that, yes, individuals who are hard of hearing and individuals who are late-deafened, are going for mental health services, and they go for mental health services for a variety of reasons, which are generally similar to those given by the general population. They seek mental health services not just related to coping with their hearing loss. However, when they go for mental health services, while the therapist is willing to accommodate their communication needs, it's done on a superficial level. It's done in a very obvious way. Therapists are trying to be good therapists. They are trying to be empathic, but are just not making it. They need to know more about how to accommodate individuals with hearing loss. They need to help the individuals advocate for their own communication needs, and not be always in a position of defending their communication needs or their experiences.

Few therapists knew about, or took advantage of the assistive listening technology and visual technology available. Most individuals, who are hard of hearing or deaf, coming to them didn't know much about it either. Sometimes accommodations were not made because the client did not know what was needed.

In addition, we found that therapists do not really understand the implications of hearing loss on the person's experiences. They tended to discount them, to diminish them, to invalidate the person's experiences. They also tended to confuse the groups, the three groups - or really four groups, of individuals with hearing loss. They confused hard of hearing individuals with culturally Deaf, late-deafened with hard of hearing/culturally Deaf, and so on. Also, it seems that therapists knew nothing about cochlear implants.

Finally, although respondents reported feeling satisfied by services offered, their need to cope better to the impact of hearing loss on their lives was not adequately addressed. The picture that is being presented is not a very positive picture in terms of the skill level of therapists. Nor a very positive picture in terms of what people are advocating for themselves. In terms of the respondents, we're talking about the cream of the crop. People who are members of SHHH, people who are members of ALDA, are generally fairly high-functioning individuals. If you think these are the results we are getting from this very select group, a group of individuals who are already accessing support services - what would happen, or what would the response look like, if we are accessing people who are not members of SHHH or members of ALDA?

We believe this is the best picture we are going to get, and in fact, the needs for training are even greater than indicated by our data. Therapists need to know about the mental health issues related to hearing loss. They are not helping individuals with hearing loss if they are saying, "But you do so fine with me!" And they are not helping individuals with hearing loss learn improved coping strategies if they are writing on paper and using that as a form of visual communication when there are far more sophisticated methods
available. Individuals with hearing loss need their therapists to encourage the use of adaptive strategies for coping with communication difficulties. Our data suggest that therapists are doing quite the opposite, largely because they don't know about these strategies.

In an effort to tap the broader population of individuals with hearing loss, we do plan to design future research projects that move outside the boundaries of SHHH and ALDA members. We are in the process of working with large university hospitals located in metropolitan areas -- for example, Howard University in Washington, DC -- which have large numbers of patients passing through their doors who have hearing loss but are not members of these consumer organizations. In addition, we hope to access minority groups so that we can understand better how hearing loss affects these groups of people. Finally, in an effort to increase mental health practionners' sensitivity and understanding of issues related to hearing loss, these results are being organized into articles that will appear in professional and academic journals. We also present these research results in the workshops and talks we conduct at conferences and meetings with mental health service providers and other professionals in the health care arena.
INTRODUCTION

Douglas Watson:

This panel presentation focuses on enhancing rehabilitation and employment outcome for adults who are late-deafened. Moderated by Dr. Douglas Watson of the University of Arkansas Rehabilitation Research and Training Center (RRTC) for Persons who are Deaf or Hard of Hearing, the panel includes: Steven Boone, RRTC for Persons who are Deaf or Hard of Hearing, Arkansas; Mary Clark, Hearing Loss Link, Illinois; Keith Muller, League For The Hard Of Hearing, New York; Cecil Bradley, Rehabilitation Services, Florida; and George Kosovich, Office for Deafness and Communicative Disorders in the Rehabilitation Services Administration, the Federal Office of Special Education and Rehabilitative Services in Washington, D.C.

The goal of the panel is to provide the opportunity for people in the field of rehabilitation to share perspectives on current and future developments in employment and rehabilitation services for late-deafened and hard of hearing persons. The panel was chosen to provide these perspectives from: the research field, direct service agencies, and the federal/state Vocational Rehabilitation Program.

There are many exciting developments in the field. As you probably know, for many years the delivery of rehabilitation services for persons with a hearing loss in the U.S. has focused on the culturally Deaf population. More recently, service programs have begun to redefine and change the populations targeted for services in this country. In part this reflects that we are beginning to recognize there are very clear differences within the larger hearing-impaired population that merit special focus and efforts by rehabilitation programs, namely that persons who are late-deafened and hard of hearing have their own unique needs. We would like to speak to these needs in this panel presentation focused on employment and rehabilitation efforts to improve employment outcome for these people. Following a brief statement from each panelist, we will open the floor for interaction, discussion, questions and answers.
I've been asked to overview the types of research that have been conducted by faculty at the University of Arkansas Research and Training Center for Persons who are Deaf or Hard of Hearing. Many of you are aware and have participated in the research conducted by our center with persons who are late-deafened. Let me thank those of you who participated in the surveys that were conducted by our Center a few years ago. The goal of this research was to develop a better understanding of the types of employment related problems faced by members of your organization. We planned to use this information to develop a series of intervention and resource materials to assist you in dealing with these problems. These materials are just now becoming available to you. I would like to describe two primary areas.

First, many persons indicated they experienced problems related to succeeding in job interviews. A large number of these individuals indicated they had lost hearing at the time they were trying to enter the labor market and thus, needed to learn how to present themselves in a positive light in job interviews. Others indicated they had lost their hearing after several years of successful employment, were forced to change jobs, and thus needed to relearn how to present themselves in job interviews. We have approached these needs by developing a number of strategies, including a video-based teaching curriculum that is closed-captioned. The curriculum targets general interviewing as well as the special twists needed to succeed in interviews if you have a hearing loss. It should be available soon for those of you who would like to improve your interviewing skills.

Second, many of the ALDA respondents expressed a number of concerns in the area of job accommodations. Many people didn't know where to begin to even think about how to accommodate their needs in the workplace. They didn't understand how to assess the situations they dealt with at work, identify a range of potential accommodations that might help in these situations, and then negotiate for these accommodations with their employer.

These problems led to the development of a second curriculum that will soon be available. This computer-based curriculum is currently being enhanced to include multimedia presentations of video and graphics in these areas. It should be available to you shortly.
I would also like to inform you that our Center has been recently refunded to conduct a new five-year cycle of research that focuses on your needs. There are five new areas of research and related training and information dissemination efforts. Many of the information dissemination activities are programmatically derived from research-based findings from our previous five year grant cycle. We will be disseminating many materials designed to translate the findings of research into products that are useful to you, like the curriculum and resource manuals we just discussed. Other dissemination activities include publications conducted with organizations such as ALDA. For example, at the invitation of ALDA, we published "Changing Lives in Changing Times," based on papers presented at ALDAcon '95.

We also offer training and technical assistance to agencies or organizations who need access to the types of expertise and skills available within our faculty. We would like to serve as a resource to you and are happy to respond to your needs or interests if possible. Some of you may be interested in graduate training leading to a career working in independent living and rehabilitation counseling with persons who are deaf and hard of hearing. We offer a Master's degree in these areas. If you are aware of persons who desire this professional education, please encourage them to contact us. We have federally-funded traineeship support to help qualified students pay their way through school. Our program is consistently rated one of the very best in the United States and our graduates are in demand throughout the country.

Finally, let me summarize for you the topics that are the focus of our new research projects. These projects have an overriding focus on four subgroups of people with hearing loss: people with late or adult-onset deafness, people who are hard of hearing, the cultural Deaf community, and persons who are from these groups and low-functioning. There are five projects:

The first project is descriptive. Our goal is to examine archival data and to collect new information that will examine the employment needs of these four groups. We hope this information will result in improved services and lay the groundwork for increased funding of these services.

The second project focuses on innovative school to work programs that emphasize partnerships of employers with educators and service providers to facilitate the transition from education to employment. We will identify effective models of these programs, and replicate unique features with persons who have hearing loss.

The third project extends our knowledge base regarding effective rehabilitation interventions. We will continue to evaluate and develop interventions such as the ones previously described.
The fourth project focuses on employers as an under-utilized resource in the rehabilitation field. We will try to identify and address the needs of employers as equal partners in the rehabilitation process.

Finally, we are interested in technology, especially those technologies that can enhance communication. Two areas of primary interest include remote applications of CART and video-conferencing. Our goal is to demonstrate how to effectively harness these technologies in service delivery.

In sum, this is an exciting time for researchers. There are many new developments that potentially can impact rehabilitation services for persons who are late-deafened or hard of hearing. Please accept our sincere offer to become involved and to advocate for the types of research that are important to you.

The Service Perspective from Chicago Hearing Loss Links

Mary Clark:

My agency, Hearing Loss Link, was started in 1994 by Bill Graham. It is a very young program, only four years old and remains one of the only agencies in the United States that is only for late-deafened and hard of hearing individuals. We offer four core services that we call CARE:

C for counseling, A for advocacy, R for referral, and E for education.

Many of the clients that we have come into our office for mental health issues. In fact, the agency was actually set up to help persons make the transition from being hearing to being deaf. This transition period is very crucial, and difficult for most people. We try to provide services that focus on issues that happen during this transition time.

People come into the office usually for mental health issues that are probably related to their hearing loss. Most of the time these people come in with someone else; they don't come in on their own. Since many individuals do not come on their own, they often don't come back. Maybe they are not ready to really face the issues that they have to deal with. Frequently we may not see some of these people until a year later, when they come back and are ready to face these issues. We have two counselors on our staff. One of the counselors only deals with mental health issues, family issues, or any kind of issue related to hearing loss. The other counselor focuses on occupational issues.

Our funding was initially from a grant from the Chicago Mayor's Office for People With Disabilities. It was a very small grant, around $20,000. Our second source of funding was from rehabilitation services, which is called the Department of Human
Services in Illinois. Finally, we received a grant from OSERS - the federal Office of Special Education and Rehabilitative Services, for rehabilitation issues. These resources have allowed us to expand from a program of two part time employees to a larger program with full time employees. For example, the day I joined the program, I was employed part time in the morning. We received the OSERS funding that day, and by the afternoon I became full time. It was an exciting first day of work. I think that was probably good luck.

In addition to the individualized caring services I described, we provide support groups which focus on people who have similar characteristics, such as Meniere's disease, age and, gender. Each of these groups needs the support that can come from shared experience.

We also have communication classes. When our clients come in and ask us what to do about communication, we don't say, "Go out and learn sign language." These are people who live in hearing situations with hearing people, so it does no good, to say, "Go and learn sign language." But we do offer speech reading classes specifically for late-deafened and hard of hearing people, and sign language classes which we call "Signed English Classes for Late-Deafened and Hard of Hearing People."

We have also started to provide socials. We find there is a large group of single people who are late-deafened. They think that ALDA people are old people. So we decided that Link should have a social, once a month for those under 40.

Finally, we sponsor workshops with the ALDA Chicago Chapter. These workshops are very exciting. Another exciting development is that we have just developed a relationship with HiTech, an organization that sells assistive technology. We are beginning to set up an assistive technology library where people can visit and borrow equipment. They can try it out, see how it looks and works.

In summary, Hearing Loss Link is providing a number of services that are specifically designed for persons who are late-deafened or hard of hearing.

The League for the Hard of Hearing (NYC)

Keith Muller:

Since many of you don't know about the League for the Hard of Hearing, let me introduce you to our agency. The agency was founded in 1910 in New York City to help people who are hard of hearing find employment. Since then, it's grown to a large international agency. We have 100 on staff, and offer a full range of comprehensive speech and hearing services as well as human services like rehabilitation and mental health. In addition, the agency is a place that anybody with
a hearing loss can come and feel welcome, no matter what type of communication they may use.

The agency has basically eight departments. We have 11 audiologists, and 10 speech pathologists, as well as a technical service department that provides a full hearing aids program. We also have a mental health social service department for career development, job placement and counseling. In addition we have a research center which is an applied, privately funded, research center, that is studying cochlear implants, psycho-social issues for children, as well as evaluating our own League programs and their outcomes.

And we have two advocacy centers - one on noise, and a second on hearing conservation, which is an area we all need to be more aware of. For example, when you go out this holiday season and buy toys for your children, examine the noise produced by those toys. Many toys produce up to 138 decibels of sound. OSHA will not allow persons to work in an environment over 85 decibels for our protection. We need to advocate to reduce the volume level of children's toys.

The League also opens its rooms to host meetings for local chapters of Self Help for Hard of Hearing Persons, The New York Deaf/Blind Association, and the Cued Speech Group. Most recently, the ALDA chapter in New York has asked us to host their program.

Another exciting development is in the area of computerization. We have set up our own home page and you are invited to look at our home page at www.lhh.org. We are very proud of our homegrown home page. We are now providing services to people in Brazil and Saudi Arabia through the World Wide Web.

So that describes some of the services we offer. Let me spend some time discussing my views toward persons who are late-deafened. The population includes several groups of people: those who are hearing and suddenly become deaf, those who are hard of hearing who become deaf and those who are hearing who become hard of hearing. In preparation for this workshop, I tried to think of the unique features of those populations. I think the most unique feature is the need for communication. So an agency that provides services has to be accessible to anyone who comes in with a hearing loss. As a result, agency service personnel have to have an attitude of tolerance, they have to be able to provide oral rehabilitation, lip-reading and voice modulation training.

Other key needs include retraining and counseling, both for the family as well as the individual. And certainly, assertiveness and empowerment kinds of programs are needed also.
Now, I would like to look at the Federal/State Rehabilitation program because they are the major provider of services to people with a hearing loss. I have been on a campaign, one that I will continue, to try to keep rehabilitation up to speed. Rehabilitation counselors in New York City, and I presume nationwide, are ill prepared to effectively deal with this population. We have President Clinton advocating for rehabilitation services in our classrooms, yet our V.R. counselors don't know how to use computers. We have assistive listening devices and technology centers everywhere, but we rarely find situations where a rehabilitation counselor offered you an assistive device when you came in for counseling. We see this as a field that must become much more vigorous in promoting, incorporating new technology such as ALD's or CART in all client contacts right from the beginning.

There are many resources available that the League refers people to, for example, ALDA, CICI contacts, and service providers like Hearing Loss Link, and Vocational Rehabilitation, and the Internet. Getting involved in volunteering is also a key element.

Lastly, I want to talk about obtaining services for your needs. Too many people still think that unless they are in a meeting with five, ten, or fifteen people, they are out of line to ask for an interpreter, to ask for CART or to ask for anything. Please, take away from here the lesson that: one is enough! You are enough in any school, any theater, any hotel, or employment situation; if you need an accommodation, ask for it. You have a right to it. That is what our Congress and our President has said to us. I encourage more advocacy on the part of the consumer to come to provider agencies like us and say, "You are not giving us what we need." Go to Vocational Rehabilitation, or whoever, and say, "You are not giving us what we need."

I encourage Vocational Rehabilitation to re-engineer. In New York we are providing CART systems in schools for children. I would like to see VR provide more CART services. ALD's are in schools, and I would like to see more of them provided also. Certainly a public relations campaign to attract consumers is urgently needed. Certainly, on a larger scale, tolerance among different groups is critical. There seems to be almost a cultism out there -- we have another sign language convert or another speech reading convert. I would like to see us get away from the idea of one "cult" versus another, and provide an environment that is loving, nurturing, and accepting of whatever works for you.

On the legislative battle, we need to work together to make sure that the Rehabilitation Act is re-authorized and incorporates some of these new technologies that we are talking about. The present Rehabilitation Act does not include this. We have been active nationally advocating to make sure it does.
Finally, let me summarize a few new initiatives at the League. We have support groups like Mary was talking about. We have Link groups where employers are linking up with mentors, and mentors who are hearing-impaired are working with students who are facing future employment. We are developing a database that is computerized. That should be very exciting for research purposes.

State/Federal Vocational Rehabilitation Perspective from Florida DVR

Cecil Bradley:

Let me give you a general idea of what VR (Vocational Rehabilitation) does. Contrary to public misconceptions, VR is not an entitlement program like welfare. VR is an eligibility program that provides services to people who need services to prepare them for employment. To be eligible, you must have a disability that affects your ability to gain and/or maintain gainful employment.

Most of you have a hearing loss and you could be considered for VR services. The critical aspect is how this disability results in functional limitations, rather than the hearing loss itself. To illustrate this distinction, Florida provided free services to 3,500 deaf and hard of hearing individuals alone, at all levels of hearing loss. But equally important are your abilities.

VR provides all kinds of services to facilitate employment. Many persons receive education and training. Others require equipment like hearing aids or perhaps, cochlear implants. Services may be used to meet any specific needs that a person has in order to obtain gainful employment.

Many times, we work with employers to straighten out any misunderstandings that may occur about the individual skills that person has to have in order to work on the job. We may advise them about accommodations that are necessary. A lot of employers are reluctant to do this, as you well know, and many employers are not willing to pay the price of accommodations.

VR comes into the picture and helps them to work out these issues. We make agreements to help with the cost. Many state VR agencies around the country have specialists like myself, who help the agencies to accommodate you. These specialists help ensure that the field counselors can provide quality services to you, which is a critical area.

We know the country has an acute shortage of qualified counselors who have a very thorough knowledge of working with persons who are deaf or hard of hearing. These skills go beyond signing. Qualified counselors must be familiar with all of the technologies used by people with hearing loss. Each persons' needs are not the same. It isn't a one-size-fits-all concept.
Each state has about 30-50 counselors who are supposed to be skilled and knowledgeable. Again, this requires ongoing training, and that's where you can come into the picture. You can help us to better understand you and your needs.

For example, in Florida, we conduct counselor/staff training twice a year. We invite individuals who have hearing loss to attend. We ask them to help us understand their issues. By their involvement, we become more sensitive, and we can appreciate each client's individual abilities and needs.

We also fund or otherwise support projects leading to enhanced services. For example, one project is focused on the needs of persons described as low functioning. Another has developed videotapes, one of which, for example, is for employers to convince them to hire individuals who are deaf.

A lot of times, VR is easily misunderstood. We hope to straighten out these misunderstandings. A major challenge are the issues relating to education. Persons with inadequate education are a challenge for VR. Many kids are not appropriate for college or higher education and thus, VR can't justify sponsoring them to attend college programs. It isn't because we don't want them to go to college, but it's because of their educational limitations. This is a sad thing to say, but VR can't fix these deficits.

The last thing I want to talk about is that it is very important that you be involved in rehabilitation. We need more and more deaf individuals, hard of hearing individuals, and late-deafened individuals to serve on advisory committees and advisory councils. We value your feedback, and a lot of times this helps promote administration and service improvements. Many people think everything is fine, but we need your input, your involvement. It truly makes a difference.

The Federal Rehabilitation Partner

George Kosovich:

I am here to talk about the federal partner, the one that you all pay for with your federal income tax. First, I just want to say that I am a very strong advocate for VR. I'm a former client of VR, a former state VR counselor for 12 years in Oregon, and I am at the federal level now. I see myself as an advocate in the Department of Education, an advocate for better rehabilitation services for hard of hearing and late-deafened persons.

This population has really been second, even third class, in terms of getting services because people just don't seem to understand that we don't all use sign language to communicate and that we are not all born with our hearing loss. So it has been a real struggle because the culturally deaf population and their advocates
and the professionals in that field have been strongly entrenched in the minds of people, the government, and the general public. There is nothing wrong with that. I think it is great that they have made themselves recognized and people are aware of their needs.

At the same time, it has kind of been an uphill struggle to get beyond that population and to expand on what people know. No, we don't all benefit from interpreter services. And no, we don't all use TTY's, and that type of accommodations. So it has been a real challenge.

I want to give you a picture of the "federal partner." We are in the Department of Education, and within that, we have the Office of Special Education Programs, and Rehabilitative Services, OSERS. Within OSERS is the Rehabilitation Services Administration (RSA) where I am located with the deafness and communicative disorders branch. In this branch of RSA, our focus is to increase services for persons with hearing loss.

Along with RSA, we have the National Institute on Disability and Rehabilitation Research (NIDRR). It used to be a part of RSA, but now it is separate. NIDRR provides funding for the Research and Training Center in Arkansas, and the Research and Training Center in San Diego. Both of these programs are focused on rehabilitation services for persons who are hard of hearing and late-deafened. The one in Arkansas is broader in scope, and also includes the signing deaf population, deaf-blind and low-functioning deaf individuals. There's a whole slew of other kinds of grants as well, that are focused on all kinds of disabilities.

The third segment of OSERS is the Office of Special Education Programs. This program is working under the IDEA, which is designed to assure that access to quality education for children with disabilities, all disabilities, becomes a reality.

So, with that, we have a picture of the federal government's special programs and office that works with people with disabilities. RSA's main program is Vocational Rehabilitation which is funded at over $2 billion a year. That's $2 billion less than what we actually need. A big problem in rehabilitation services is the lack of funds. There's just not enough funds to serve the people that want, and need, rehabilitation services.

Consequently, everybody gets cut back a little bit so we can serve more people. Some people say rehabilitation is not working. It is working for some people, but because of funding shortfalls it's not working as well as it could.

So what can we do about this situation, especially regarding services for people who are late-deafened or hard of hearing?
I think there is a lot of advocacy that needs to happen. The Council of Organizational Representatives (COR) in Washington, DC has been involved with that. RSA has had the opportunity to meet with COR. COR represents NAD, SHHH, ASHA, RID, A.G. Bell, and a bunch of other organizations. ALDA is not represented in CORE, but personally speaking, I believe something should be done about that in order for CORE to get access to a better representation of the late-deafened person's perspective.

So it is important that COR comes forth and talk to the Assistant Secretary of OSERS, Judy Huemann, who is a very strong advocate for people with disabilities. She has been very supportive of the deaf community population, and is just now really beginning to understand, or become aware of, the needs of hard of hearing and late-deafened people. I think it's a real good time for people with ALDA to make an appointment with Ms. Huemann and the Commissioner of RSA, Fred Schroeder. Let them know what your needs are.

For example, the Rehabilitation Act is now in the process of being re-authorized. If it's not re-authorized, it will carry over into fiscal year 1998. But if it's not authorized after that, there is no more rehabilitation program. So people need to get out there and advocate.

There are many persons you could directly contact to advocate for your needs. Judy Huemann is the Assistant Secretary. Fred Schroeder is the Commissioner of RSA. There are ten regional offices, each with a regional commissioner.

To close, I want to emphasize that I think the Federal/State VR program is essential for many people with disabilities, including a lot of people with hearing losses. I say that knowing that rehabilitation basically saved my life. I was really on the fast track to nowhere when I came under VR services and it really helped me a lot. I suspect some of you have probably not had as good an experience as I have had. But problems can be resolved. I just want to add that we have the Client Assistance Programs (CAP) as a resource to assist those who have not been satisfied with the services they received.

The Client Assistance Program is funded by RSA. It is supposed to be separate, even though in some states, it is located under VR. Some people question whether that is a good idea or not. CAP serves as the advocate for the clients, those applying for services and getting services. If these persons are dissatisfied with their VR counselor or program of services and decisions that are being made by the state VR people, they can go to CAP. CAP is basically a mediator between the state agency and the client. They are supposed to be there for you and supposed to understand where you are coming from, and advocate on your behalf. If you are not happy with CAP, then I think the next step is contacting your regional RSA office.
Let me end by restating I am glad to see so many people here. I hope that we can get ALDA in a position to advocate more strongly for people who are late-deafened in the future.

Discussion:

Keith Muller:

Whenever I hear anybody say, "We don't have enough money," I say, "I agree with you." But when I hear someone say, "There isn't enough money," I don't agree with that. The problem is, we have not been successful as a community in getting the money that is available. Money is being spent everywhere else. We have to get together strongly as a group and go after the money, because the money is there. If we are not going to use the money, someone else will use it, I guarantee you.

George Kosovich:

"Order of selection" is an issue about money. I think that the "order of selection" comes about when a state sees that they don't have enough money in their budget to serve all the people who apply and are found eligible for services. So you end up with people being on a list because they don't have the money. They follow a formula that is derived by the Rehabilitation Advisory Council and the agency together, to determine how they are going to go about funding which people, and defining who is the most severely disabled. You can't really say any population group is any less disabled than another population group. You just can't do that.

If that's happening, and it probably is in some states, you need to make some noise; especially as it relates to people with hearing loss.

The people who do not seem to be severely disabled "enough," or those that are judged "most severely" disabled, often wind up on a waiting list. The key question is how is this determination made. Is it the severity of the impairment or the severity of the disability? These are two very different things.

If you have no hearing, then you are going to have a "severe" disability. If you have a severe degree of hearing loss, then you have a "severe impairment." But how you function may be a another story. For example, a person with a doctorate degree and twenty years of experience, who can use an interpreter, or is a good speech reader won't be as disabled as somebody with a moderate hearing loss who is in denial, doesn't know the first thing about how to cope, resists wearing hearing aids or using assistive listening devices, and has high school diploma and limited experience.

So it depends upon not only their background but on their ability to function in different situations. Just because somebody is born totally deaf doesn't mean they
are more disabled than somebody with a moderate hearing loss, who can't get a job because of the reasons I just discussed.

A lot of people look at one group of people, for example those in wheelchairs, and say these people are more severely disabled than a hard of hearing person. You can't do that. You have to take each individual into consideration, how they function, and what their rehabilitation needs are.

From The Floor:

I went through the Vocational Rehabilitation Services in Florida to get my cochlear implant during the past year. I was led to believe that it would take only a short time to do that. I delayed starting my own business to wait to get the implant. It took a year to get the cochlear implant. In the process, I lost my business. I was not informed of the wait. And I think it would be best to communicate that wait to the individuals.

Keith Muller:

The issue of eligibility for rehabilitation services between states comes up a lot. If you are in New Jersey, and you have a different hearing loss, say a moderate to a mild hearing loss, you are eligible in New Jersey for more rehabilitation services than you would be if you lived in New York. So we have people who are coming to the League who live in New Jersey who want to work in New York, and they get jobs. But we have people in New York who have the same hearing loss as someone in New Jersey and can't get VR support.

So part of COR's activity is to try to have the Federal/State VR program develop some minimum standards across states so that this type of situation doesn't exist. We are having a very hard time getting that to happen. Perhaps ALDA and others could work to compare neighboring states in terms of how they determine eligibility; find out how much of a difference there is. Perhaps we could all get together and have some sort of standardization for this increasingly mobile society in which we live so that this sort of thing doesn't happen.

Steve Boone:

It seems like a lot of what everybody, both participants and panel, is saying is that we need better communication, better advocacy, and better sharing of particular information. There are a lot of new strategies for sharing this information. One is via web sites. You have information on our RT-31 web site on the handouts we gave you today. I know you have information on the web site from the Research and Training Center in San Diego and also at The League for the Hard of Hearing. There are a lot of different places where you can get information.
Let me sort of tell you that as a researcher, one of the key problems that we all face is keeping that information current. I realize everybody on this panel is truly in the business of trying to improve services for you.

There is one little simple way that you can help us. I would like to ask you to take just a few minutes to think about the questions we have raised. If there is something that you think we need to know, please feel free to contact us. Let us know how we can help you address those kinds of problems. That is a key part of doing good research: your involvement. I can sit back and dream up research, but if what I am doing is not responsive to your needs, if it is not what will help you to get the rehabilitation services that you need or get you an employment situation, it won't help. So please be more responsive. I encourage you to think about that, and to go out to the people in your local chapters, talk about those things and get that information in to service providers. Get that information in front of the research community. Let us know so that we can try to do what you would like us to be doing in good valid scientific ways. So please use this opportunity to do that. I know our RT-31 program, and all the programs represented on this panel, would like for you to do that.

Closing Comments from the Moderator

Doug Watson:

The University of Arkansas Rehabilitation Research and Training Center for Persons who are Deaf or Hard of Hearing has a national mandate to try to improve the training of rehabilitation and other personnel in serving the population that ALDA represents. Our Center previously helped develop and disseminate special training packages that were designed to teach rehabilitation personnel how to better serve people who are deaf or hard of hearing. These were called "Orientation to Deafness," or "Serving Individuals who are Hard of Hearing;" short-term training programs designed to teaching rehabilitation personnel how to better serve people who are deaf or hard of hearing.

What we don't have, and what we would like to have is for some of the ALDA members to work with us on, is to put together a training package that would be targeted more to teaching rehabilitation personnel in the 50 states about ways and means that they could better serve the needs of people who are late-deafened. In order to simply put together such training materials, we find generally it is not enough to put together some national guidelines, or training material, and package it with videos and teaching curricula.

We have learned that we also need to reach out and involve consumer representatives and consumer advocates as co-trainers. We believe these are the people who should be encouraged and assisted to take charge and set up training
seminars in their respective states, assisted perhaps by rehabilitation personnel, and trainers from interested colleges and universities that have a shared interest in training professional personnel to serve individuals who have experienced an adult-onset hearing loss.

We are very interested in working with ALDA, and you individually, or your state, over the next several years, toward this objective. We envision the task to include the development of comprehensive training packages that will include materials appropriate for people who are deaf (cultural Deaf community), as well as those who are hard of hearing or experienced adult-onset deafness.

Trying to combine training that encompasses the unique and different needs of the three groups is a major undertaking. We believe such a training approach is needed and that it could then be adapted for use by various groups, depending on the interest and the needs of a particular training group.

We see the same need in terms of the rehabilitation counselor training programs that Keith Muller referred to earlier. Our Center operates two long-term degree training grant programs from the Federal Rehabilitation Services Administration. We recognize that RT-31 and other counselor training programs do not provide enough training emphasis on the unique needs of people who are late-deafened. In other words, in terms of training rehabilitation personnel to serve late-deafened individuals, we acknowledge the need to develop a better understanding and knowledge about how to deal with, and work effectively with, people who are, in fact, late-deafened. We see this as a very important contemporary challenge to our field. Only about ten major university training programs in the country are training rehabilitation professionals to serve deaf, late-deafened, and hard of hearing clients. For me, I see it as a relatively logical next step to ask those specialty training centers to work together toward the common goal of adopting a common training curriculum that we can then incorporate into our respective training programs around the country.

Universities throughout the country that provide most of the trained personnel who are specializing in deafness rehabilitation include programs such as: Gallaudet University, New York University, University of Northern Illinois, University of Arkansas, University of Tennessee, San Diego State University, California State University at Northridge, University of California at San Francisco, and Western Oregon State College of Education.

In order to add an emphasis on late-deafness to these programs, they need to cultivate partnerships with consumer representatives and others who can help us speak for the members of the population. The goal would be to develop sensitive, appropriately targeted and organized training materials that can effectively teach
rehabilitation personnel the knowledge and skills they need to effectively serve individuals who are late-deafened.

What we are trying to say is we would like to work with ALDA. The field of deafness rehabilitation would like to see training programs and direct service programs get together with late-deafened consumer representatives to establish a productive partnership with ALDA. The objective being to improve the delivery of rehabilitation and related services to late-deafened individuals in the United States.

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CART  
(COMPUTER-ASSISTED REALTIME TRANSLATION)  
TECHNOLOGY FOR TODAY AND TOMORROW

Heywood “Woody” Waga and Marylyn Howe

Woody Waga:

CART stands for “computer-assisted realtime translation.” Basically when most of my deaf and hard of hearing friends go home after work and watch the news or their favorite TV show, they are watching CART, but in a different format called “closed captioning.”

Let us discuss very briefly the distinction between closed captioning and open captioning. Open captioning means that as something is being said, it is also being displayed, and you really can’t turn the captioning off unless the operator stops writing. With closed captioning, on the other hand, you have the ability to turn off the signal with your remote control device on your TV set. You just click the button and you are back to television without captioning.

This bring up a most fascinating 1997 question in my opinion: should the movies in theaters be captioned? Why shouldn’t they? Why should only art films be captioned? No one seems to object when a French or Italian movie is displayed and there are captions in English. People read the captions. Why can’t English, which is probably the largest used language in the world, be displayed for all people to see, whether we are talking about 28 million deaf and hard of hearing Americans, or 550 million hard of hearing and deaf people in the world? Why couldn’t those people watch the same movie that I watch and not have to wait until that movie is reduced to a rental movie in your local Blockbuster movie rental store? Isn’t that what the ADA is all about?

There are other extensions of this application. One is children who are mainstreamable: that is those who are able to go to a traditional school but who are also deaf or hard of hearing. It is very difficult for me to have credibility to talk on this subject because I am not deaf nor hard of hearing. I do not know if I can accept the decision to keep children in a school that only serves deaf and hard of hearing children, because many of us know that some of the children do not read very well, do not socialize, do not play sports, or date. Very often they are isolated. This brings us again to the basic concept of the ADA: fair play, equal access, and reasonable accommodation.
There are all those two-word phrases that fit right in. Not being a deaf person, how can I gain credibility? I don't need credibility. Frankly, I don't want to be deaf. I don't want to be Greek. I am just what I am, and I'm trying to render a service that hopefully will assist many people in fair play, in communication access.

If you agree with that, you might want to get the word about this across in your community. How to do it is very difficult in our society. One of the ways to do this is to do what we did in my home state of New Jersey. We began a Communication Access Group, which included educators, court reporters, interpreters, government officials and advocates.

We met once a month. At first the going was slow because many of these fine interpreters and the court stenographers thought they were competing with one another; and only after much talk did we realize that we do not actually compete. An interpreter cannot do what I do with CART, and I cannot do what an interpreter can do.

But we needed a meeting to talk about this and write about this, and really come to understand the fact that we both cater to the deaf and hard of hearing community, but differently. They speak their language, and we speak ours.

After that understanding was achieved, the group was so organized that we didn't want to let this group go. We began to think that maybe there is something else we need to talk about -- such as more communication access. So we invited the Commissioner of Deaf and Hard of Hearing Services in our state to join us; and he brought with him the local chapter presidents of the National Association of the Deaf, Self Help For the Hard of Hearing, A.G. Bell Association for The Deaf, as well as the presidents of other various organizations. They joined with us and we started to speak about how more communication can be made available to those with hearing loss.

Brilliant minds think alike sometimes. One person doesn't think of all the ideas, but 20 people in a room served salad, sandwiches, and coffee come up with wonderful ideas.

Then I brought the court reporting community in and began to talk to them about CART and expanding beyond only doing legal court reporting. The interest began to grow. I believe in New Jersey, we are probably one of the only states that has this, a Community Access Group.

So what we are doing now is going to our national association and introducing this concept nationally, so at their state leadership conference, the national organization can influence various state leaders to go back to their states and start their own
communication access initiatives, and invite the same people to their meetings that participated in New Jersey.

I will give you another concept that is coming up in New York City right now. I live in New Jersey, maybe 11 miles from New York City. If you think of New York City, you think usually of Wall Street, money, crime, and dirt. You also think of theater and Broadway. Deaf and hard of hearing people don't get a chance to enjoy the theater with its music, lyrics, and wonderful productions. But there is a device, a piece of technology, called silent radio that's not totally compatible with all of the computer systems that CART reporters use, but it's compatible with a few. Using this device you can store the entire script of a play in the Silent Radio neon sign. And as the words are being spoken, you can feed them out by merely hitting a little button.

So you might not be able to hear all of the songs or music, but you can read the words. Many times, knowing how loud theater can be, you feel the beat in the floor of the music. If you have gone to a karaoke party, you will know what I'm talking about. You will feel the beat of the music and people dancing. Very often, as far as late-deafened adults are concerned, you often remember the songs that you last sung before you became deaf. That is what theater is all about.

Now I want to talk about the sensitive and personal aspect of being a CART stenographer. We want to be perfect. It's not hard to find a mistake; the spelling of a name, the name of a country, the derivative of a word that we always use, people tag on different endings to words and create their own little vocabulary -- all of these things can contribute to mistakes. Perfection is not always in that little black machine run by 10 fingers, two ears and one mind. Doing CART well is very difficult and stressful.

If you do see a mistake, it's okay to chuckle, and then remember that it's not the worst thing in the world. We do so much preparation for our task. Every assignment that CART reporters go on, they specifically train for that assignment. When I say, for example, the word schistosomiasis, a very rare disease, if prepared the reporter might have schistosomiasis written correctly. But if not, it might come out incorrectly. In addition, if a wrong combination of keys is hit, you might get a four letter word that you really did not want to see.

So please understand that this is still an art; and art is not perfect. It will never be a perfect science. We are trying very hard to perfect our skills. There is also the fact that most captioners were trained to work in the legal and judicial system.

A real difficulty we have in the court reporting community is introducing new reporters into your community. What I really believe we all need, my people, your people, and all the people outside -- mostly the people outside -- is an awareness
program. That's what we all need, to understand that there are other cultures living within the large majority culture. If we give each other a chance, I think we have a great possibility of success.

I was thinking the other day of the various assignments I've done in the past 10 or 20 years. One very challenging assignment was only about one year ago. There is a competition in America called "Life Smarts." It's a competition of the smartest teenagers in America. One of the competitors was profoundly deaf. He's a 16-year-old boy from Denver, Colorado and he was competing in Philadelphia. It was very much like the show we watch called "Jeopardy."

He and four other people were representing their state, and they asked me to caption the entire show so he could read the questions. As you may know, the second the question is asked, you press a button, and the one who responds first gets to answer the question. I was too slow. I really wasn't too slow. The split second of time between the time that my fingers touched the machine and it appeared on his computer screen was too long for him to be competitive.

This was a smart young boy with a genius IQ. He filed an objection and said I wasn't fast enough. After we did a test in front of thousands of people, I admitted that my technology was too slow. It was not coming up in enough time for him to respond.

So we thought of another way around it, and that was I would have the question in front of me a split second before the moderator spoke it, so that as the words are spoken the boy can see the question and answer. The very first time we did it in this way he was right in the thick of it.

He lost the competition, but he was able to compete on an equal footing with everybody else. At the end he walked over to me and shook my hand and said, "Thank you for helping me, even though I lost." That was a very, very sensitive moment, because it opened up everybody's eyes in that room that he was just as able as anyone else.

What we are doing nationally right now is introducing new technology, and to do that we need organizations. ALDA is an organization that brings self-help to you, for example; and we court reporters also have our own state and national associations. A very dear friend of mine, who represents the National Court Reporters Foundation which is an arm of the National Court Reporters Association and has 32,000 members, is a lady by the name of B. J. Shorak. She is Executive Director of the National Court Reporters Foundation. This lady is personally responsible for introducing programs and finding the money to make captioning programs work nationally. Without her assistance, a lot of this stuff would not get done. With her assistance, captioning has spread to many areas where it was never used before.
One of the most important areas to me is education. We are now captioning in colleges, universities, high schools, and even grammar schools. We call it "classroom captioning," and we actually take the same technology, and give the person or persons their own computer screen with nice large text. They sit there and they read what they cannot hear. We are working with a girl who had a cochlear implant at 2 years old. She's now 11. She was on "60 Minutes." And she is at the top of her class. I'm glad to be a part of the movement that's making this possible.

There are conferences every day of the week in corporate America, in government and in associations like this. We have conventions and meetings where no one should be left out. And maybe it took the ADA to make sure that none will be in the future as they have been in the past.

Marylyn Howe:

I want to tell you about a program called Partnership Between the Commission for the Deaf and Hard of Hearing and CART Reporters that we set up in Massachusetts. In Massachusetts we have access to CART reporters almost whenever we need them. The program works like this: If I am having a staff meeting on Friday, and I need to have a CART reporter assist me so I can communicate with the rest of my staff, I call the Massachusetts Commission for the Deaf and Hard of Hearing and request a CART reporter (the same way you can call state commissions for the deaf and request an interpreter). They have a program set up where they have a list of CART reporters who are available to serve me, and will, if I put the request in early enough, assign a CART reporter to assist me at my staff meeting.

Massachusetts was the first state to set up a program like this, and I think it began back in 1990. And it's been a boon, it's been a real asset. We keep track of all of the requests that the commission gets, and how many of those that have been filled.

If you look at every year from 1990 up through 1996, you will see a huge surge in of the numbers of requests that come in, and the numbers of requests that get filled. So the program keeps growing and growing and growing. Our problem now is we don't have enough CART reporters on the list. There is a shortage of them. Many of them have gone into the colleges and universities -- Boston University, Harvard, MIT for example -- and they are committed to working there. So they are taken off the list by the commission. But they are still doing CART work.

But it's a fabulous program. I would really love to establish something like that nationally, where every state has a program like that.

Now, this program started because the Boston chapter of ALDA, the Massachusetts Court Reporters Association and the Massachusetts Commission for the Deaf and
Hard of Hearing got together and sat down and decided to develop the program. We had to hash out a lot of different things: the costs, how we were going to make the demand, and then how are we going to make the supply side of it work. It was a big challenge, but it has become a phenomenal program that works very, very well in most cases.

Living in Massachusetts I have become very spoiled, of course. When I travel around the country going to a lot of conferences which I need to do on my job, and I don't happen to know anybody who does CART I call Woody. Woody has his own network, and he's able to find somebody for me usually at those particular occasions.

But I also need to advocate for myself, and I need to tell the conference sponsors what I need. Now very often you get invitations to conferences where it will say check off here if you need a sign language interpreter. But there is nowhere to indicate if you need a CART, unless you are coming to ALDA.

So what I do is I check off the box, and I cross out sign language interpreter, and I write in CART reporter. But that's not enough. Because most likely they are not going to know what I'm talking about. So I fill in, "I need a CART reporter. If you have questions please call me" at my number, my office number.

Now, they usually don't call, perhaps because they don't understand what CART is. So I make sure to call them at least 3 or 4 weeks prior to the conference and say, "Did you get my request for a CART reporter?" They then usually, very nervously, say, "Yes, what is it?"

I then try to explain the process and say, "If you don't know anybody up there, I will probably be able to find somebody that will assist me, but under the ADA, you have to pay." They have to provide my communication access.

Sometimes there's a battle over that, sometimes there isn't. I don't even deal with it. I let Woody deal with it. But the important part is at least for those of you who live in the United States, under the Americans with Disabilities Act, you have a right to CART. You have a right to communication access.

Let me read a little of the ADA to you. It says that the Americans with Disabilities Act requires that appropriate auxiliary aids and services be furnished to ensure that communications with persons with disabilities is as effective as communication with others. The Department of Justice has added video text displays, computer-aided transcription services and open and closed captioning to the list.
It's right there. It's in the law. You have a right to communication access through the transcription service of CART. I use this whenever I need to; I'm not shy about requesting CART services!

So that is the most important thing I want to get across -- that we need to advocate, that it's possible and that it can happen. But you need to see that it happens. You need to do it for yourselves. If you find the right people in your home state who are willing to sit down with you, like Woody's club, it is full steam ahead.

What we did in Massachusetts was make sure that the Court reporters who were really interested and wanted to become CART reporters received special training. That training included working with the deaf population, working with late-deafened people. It included mentoring -- included them coming in and doing a self test. They would bring in their own steno machines and computers, and as we were presenting, they would be keying in and testing themselves to see whether or not they had skill. If they were really nervous, and decided they didn't want to do it, that's fine. There was no pressure. But we were trying to open it up and make it as successful as possible so we could get more CART reporters on our list. The number has increased -- we started out with about 4 or 5 CART reporters -- and right now we have something like 15 or 16. That's not including the folks who are in universities doing the college jobs.

I am going to ask Woody if he would just come up and talk somewhat about the ethics of CART Reporting. Because I do rely on our CART reporters for self help groups, and we need to understand that they have a vow of confidentiality.

Woody Waga:

CART Reporters follow the same strict code of confidentiality that all interpreters follow. It's back to those same two concepts again: Fair play and common sense. When we work in self-help groups, it's like going to an Alcoholics Anonymous meeting. What we hear stays in that room. What we capture or caption stays in the computer and when the job is done, totally erased. Even if we have the permission to release a tape, we won't release a self-help group tape because names are used in that group. That is confidentiality.

In addition, our code of ethics says that the rule is that you don't go out of your role as a CART reporter. For example, if one person were saying to the other: "After the session, let's have a drink together," and the other person then said, "Did you call me a banana?" That is the kind of conversation I could really clear up and say "No, she wanted to buy you a drink." But I have no right to do that. It's your communication, and we as CART reporters cannot intervene. On the other hand, if it were a social setting and we were just three people sitting there talking together,
that's a whole different story. But, on the job, we are trying to do a very professional and objective job.

Preparation is also very important. I am a Jew, and I captioned the funeral services for one of your very dear members who is a friend of mine. He is a Methodist. His father died, and I did the funeral services. In order to prepare, I went to a Baptist minister, and he gave me all of the funeral service rituals and hymnals. That was a word that was not in my computer dictionary: "Hymnal." I put it in and made sure it came out right.

Speaking of equal access, there's something you should know. With the new regulations of the Federal Communications Commission that will be effective January 1, 1998, more and more local television will be captioned. Right now a tremendous amount of television is captioned, and that is because most of television is pre-taped. Pre-taped television has the luxury of doing it off line, so it comes out captioned. But all of your live news will be captioned.

I am often asked how to stimulate awareness of the need for CART (rather than sign language) for late-deafened people. Especially if there is no department of deaf services available to help. There are in such a situation usually other avenues of help available. For example, there are chapters of such groups as ALDA, SHHH (Self Help for the Hard of Hearing), or a chapter of the National Association for the Deaf. Those are resources that can be used. Also, you can contact me, and I will, in turn, contact your state, whatever city you are in, and tell them that there is a need for CART services and encourage them to call you back.

Question from the floor:

Most people who hear about CART are concerned about the cost of CART. They always feel -- they know that if they hear about CART, that the cost of providing CART is more expensive than the cost of providing interpreters. So we could certainly say, "You have to do this, this is the law." But is there a way of pushing them to do it without shoving it down their throat, that the law is that you have to do it?

Woody Waga:

This is a question that we cannot talk about publicly. We cannot talk about regulating fees or how much we charge, because it is really in violation of the federal antitrust laws. But I can say that these people don't earn enough, and we don't earn enough to pay for all of the hours and tears and technology that we've invested.
But I can also say that the price of oranges in Florida is a lot less expensive than the price of oranges in New York City, because the oranges come from Florida. The cost of living is greater in the northeast than in the southwest. So prices will vary according to what city you are in.

Very often also, interpreters will spell each other. In other words, maybe work 30 minutes on and 30 minutes off. And very often the price that a CART reporter charges is approximately in line with the cost of the two interpreters working the one-hour shift.

Marylyn Howe:

I want to respond a little bit too, because I can tell you how it started with me. The very first time I saw CART in action, it was absolutely fabulous, at a national court reporter convention in Florida. I was so moved I took that experience home with me to Massachusetts and started calling the deputy commissioner at the Commission for the Deaf and Hard of Hearing and said: "Why can't we have something like that here?"

She was listening, paying attention. She herself was big on technology, and she had had a grandfather who was late-deafened, and she had a lot of interest in seeing what we could do.

So you never know who you will be talking to. You could call up or do testimony to your public VR agency. You could provide testimony at some of their public hearings or write a letter to the commissioner. You never know who is going to be paying attention to you. Any other questions?

Comment from the audience:

I would like to link with what you are saying. We've found that it's very helpful to partner with other organizations when you are trying to get points across or trying to get funding or programs initiated.

Woody Waga:

Sometimes, by networking -- we call it "bridging," the best people to call are people that you trust. The first person to call is someone who has used CART in that area before. The next person to call is a CART reporter that you know in your area if you are traveling to another area. If you want to know the best hotel in the city of Seattle, you would call somebody in Seattle and say, "What is the best hotel? Give me your best recommendation."
Also, The National Court Reporters Association has a program to certify realtime reporters, and has a free list of the reporters around the country who have been certified to do realtime. This does not mean that all those reporters listed have done realtime, it doesn't mean that they are the best at providing CART services, but it is a beginning. It's listed by state, and it's at least a place that you can call to find out if they are used to providing CART services.

Marylyn Howe:

I think we need to be very clear of the need for CART. In Massachusetts when we started in 1991 we had 86 requests for CART. In the next fiscal year there was 126. It jumped up in 1994 to 656. By 1995, it was 660. So in that five-year span we went from 86 requests to 660. Of those 660, 575 were filled. So that's an 87% filling rate too. These statistics show you the need. It's there. And I think it will continue to grow.

Woody Waga:

That's a very high percentage. My office does this every day. I think in the last year we turned down only two assignments. We've covered everyone, except those two because they did not provide us with background information that was necessary for us to do a good job in putting together a glossary of terms or organizing the technology they needed.

It's very important to know your technology, know your ability, and don't go into something unprepared. Through technology and positive attitude, communication access can be achieved.

Contact information:

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992-4111 Voice.

National Court Reporters Association
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In this paper we are going to discuss the Internet just a little bit, and then introduce, and concentrate on, the World Wide Web. We will discuss a few positive and negative features of the Web, homepage construction, Web browsers, search engines, and Web guides. Last we will identify some resources on the Web that are particularly related to hearing loss.

What is the Internet?

Technically the Internet is the network of individual computers and computer networks that use the Internet Protocol (IP) for sending data between computers. Throughout the world there are a large number of different kinds of computers using different operating systems. In order for all of these computers to exchange information, they must have some common language. In an analogous sense, if one person could speak English, another person could speak Japanese, another person could speak German, and yet another person could speak French, there would be no way for those four people to talk to each other unless they knew a common language. The common language of the Internet that enables computers all over the world to send data back and forth is the Internet Protocol. The Internet protocol is a very technical protocol, but fortunately it's really not necessary for a person to know anything about it in order to access and use the Internet.

How did the Internet start?

The Internet started about twenty-five years ago as a network of the U.S. defense department called "ARPANET." That was an experimental network that was really designed to withstand outages due to a nuclear missile attack. The situation was simple. The United States government ran by computers; computers controlled our guided missiles; computers controlled our strategic bombers; computers controlled almost everything. What would happen if the then Soviet Union dropped a nuclear warhead on Washington, D.C. and destroyed the city including all of its computers? Could the federal government continue to function? The research problem became to develop a computer network that would continue to work even if Washington, D.C. was hit with a nuclear weapon. That experimental network was the beginning of what years later became the Internet.
How big is this thing called the Internet?

It's really big. The Internet spans most of the world today, and includes more than 70 countries around the globe. It has an estimated 119 million users around the world, of which over 63 million are in the United States alone. And just one of the networks that makes up the Internet, namely the National Science Foundation Network (NSFNET), transports over 20-trillion packets of data per month. So hopefully that will give you some idea of how big this thing called the Internet really is.

There are lots of different applications or so-called services on the Internet, such as electronic mail, remote login, and the file transfer protocol (FTP). One of the services is the World Wide Web, and that is the only Internet service that this paper will discuss. To talk about all of the Internet services would require a book, so the focus here will be limited to the Web.

What is the World Wide Web?

The Web consists of millions and millions of electronic Web pages, written in hypertext markup language (HTML) residing on computers scattered all over the world. These Web pages are interconnected with hypertext links, so that a person can move from one to another quickly and easily.

The Internet evolved in part to facilitate discussion among scientists and engineers. As a result, there was a lot of textual information that users wanted to share. A way had to be found for somebody to show a document to somebody else halfway around the world. HTML was developed to connect documents and make them available to users from all parts of the globe. Again, HTML is the somewhat technical computer programming language that makes the Web work, but you really don't need to know anything about HTML in order to access and use the Web.

Sometimes people need to know how to find a particular document on the Web. Fortunately that task is made relatively easy by use of what is called a Uniform Resource Locator (URL). A URL has basically three parts, all of which are separated by one or more delimiters (slashes). For material on the Web, the first part is http - meaning "hypertext transfer protocol." The second part is the domain in which the computer is located, that is, the address of the computer. The third part is basically the path on the given computer that leads to the hypertext document in question. So, for example, the URL http://www.siu.edu/departments/cola/polsci/faculty.html would lead one to a document giving brief biographical sketches of all the faculty members in the Department of Political Science at Southern Illinois University at Carbondale. Henceforth, URLs will be specified for Web information throughout this paper.

There are several positive features of the Web. For example, the World Wide Web is totally egalitarian. Anyone, absolutely anyone, with Internet access can create a Web
The information that is available on the Web is almost endless. For example, if you are going on a trip to Chicago you can check the Web to find out if the Cubs will be playing baseball on the days that you will be in town (http://www.cubs.com/index2.htm). You can find out the current opening and closing times, as well as admission prices, at the Field Museum of Natural History (http://www.fmnh.org/info/visit.htm) or other important tourist attractions that you plan to visit. You can check the Web to see if one of your favorite attractions is located in the city, such as a microbrewery (http://www.mcs.net/~shamburg/cbs/cbslinks.html). Or you can check the weather for Chicago on the Web to see what kind of clothes to take on your journey (http://www.intellicast.com/weather/ord/). All that information is available on the Web, and it is up to the minute. That's one of the good things about the Web.

However, all of those good features don't come without a cost. There are a couple of negative features about the Web. First, most of your Web sources are unknown. When you go to a Web site, you seldom know who put that information up there. It could have been an honest person; it could have been a dishonest person. The person could know their facts, or the person could simply be guessing. You often have unknown sources with unknown data accuracy. You can spend a lot of time trying to make sure that you use only accurate and reliable Web sites, but you never know for sure.

Some people have a problem with the nonlinear logic of the Web, but it's usually a source of confusion only for people starting to use the Web. For example, the English language uses a linear logic. Words come one after another after another after another. There is a beginning of the sentence, and there is an end to the sentence. That is a linear logic. On the other hand, the Web's logic is not linear. One can start at one place, go to another in a different country, go to another on a different continent, go back to the first Web site, go to a different place inside that Web site and look at another document, and then bring in a document from a Web site on the other side of the world — and do all of this cyberspace traveling almost instantaneously. This confuses some people because there isn't a beginning and an end. It's like looking at the stars in the sky. Your eyes can bounce from one to another but there isn't a beginning and an end, and that nonlinear aspect bothers some people.

The Internet has been called the "Information Super Highway," and you can also think of the World Wide Web in terms of a real highway system. Once you are driving on the Web, you can pull off at any Web site (exit). You can then get back on the Internet where you
were, or you can turn off on another street, and then another street, and another street, and so on. How do you get back to where you were after you have turned off on so many different streets? That is confusing for some people because it's not straight from point A to point B. If you pull off on an off ramp and turn on to a variety of streets you can get lost easily.

The URLs (Web addresses) are ever changing. That is both good and bad. It demonstrates the fact that Web sites are constantly being maintained and updated, but it can be a source of frustration.

Last, the audio clips at most Web sites are not accessible to deaf people. In other words, most Web sites that play music or show movies don't display captions. Accordingly, people who are deaf don't know what's being sung or said in the materials on the Web site.

All Web sites begin with what is called a "home page." But how do you build a home page without knowing HTML? Fortunately you have several options available to you. For example, if you are on AOL you can simply click on "keyword" and then go to "my home page." They have free software there (Personal Publisher) that helps you build a home page. Your homepage can start out really simple, and then you can add or change things later. If you are on AOL, they give you two megabytes of room for your home page in a place called "my place," and that means you can include all kinds of things in your home page. However, you don't want to be too elaborate, because if you are it can take a long time for your page to download and people will have to wait and wait for it to appear on their computer screens.

You can also use other places to develop free home pages or get information about constructing home pages. For example, there is a place called Tripod at http://www.tripod.com which will provide you with space to build a free home page. Tripod gives you two megabytes of space and provides easy software to use called "Homepage Builder." Another place which will provide space and software for you to construct a Web site is GeoCities at http://www.geocities.com.

One might wonder how places like Tripod and GeoCities could provide space for you to build and post a home page for free. The answer is that they solicit and display advertising that provides the money to run the business. So if you access Tripod or GeoCities you will always see small ads on your screen. That is how those businesses can provide you free space for your home page.

When you are building a home page, there are a lot of different programs that you can use. Two of the most popular ones are Microsoft's FrontPage '97 and Microsoft Publisher '97. NetScape Navigator Gold includes an editor, which can be used to build home pages. NetScape Communicator includes a composer, which is a type of editor for building home pages. Claris Home Page is another program that can be used to easily build home pages.
In contrast to programs which can be used for building Web pages, if you want to access the information that's available on the Web you need what is called a Web browser. A browser will go to wherever you specify on the Web, locate a desired hypertext document, and display it on your computer screen. It will also allow you to download a copy of the document to your computer hard-drive or floppy if you so desire. The two most frequently used Web browsers on the market today are Netscape Navigator and Microsoft's Internet Explorer.

The Web is in effect a mega-library of virtual information that spans the world. But like any library, the user may at first have a hard time locating the specific piece of information that they desire. In a real library you probably begin your search by heading for the card catalog. Similarly, when you are trying to find information on the Web you most often use what is called a "search engine" or a "Web guide." And like the card catalog in your hometown library, you can search the Web for information by subject, author, or title.

There are different kinds of search engines and Web guides.

Some of the most popular search engines are:

- Alta Vista → http://altavista.digital.com
- HotBot → http://www.hotbot.com
- AOL's Netfind → http://www.aol.com/netfind
- Electronic Library → http://www.elibrary.com

Some useful Web guides include:

- Yahoo → http://www.yahoo.com
- Excite → http://www.excite.com
- Lycos → http://www.lycos.com
- Infoseek → http://www.infoseek.com
- LookSmart → http://www.looksmart.com
- Snap → http://home.snap.com

Many of the Web guides incorporate a search engine, like Yahoo incorporates the Alta Vista search engine, so it really doesn't matter if you call these services a "search engine" or a "Web guide." Which search engine/Web guide you use just depends on your preference. But either a search engine or a Web guide is probably all you would ever need to get started and find all of the information that you could ever want on the Web.

One thing that should be explicitly pointed out is the fact that different search engines often produce very different results. For example, at the time of this writing, when the word "deafness" was entered as the search keyword, the following results were obtained by various search engines:

- LookSmart - 11 sites
- Yahoo - 41 sites
- WebCrawler - 516 sites
- Infoseek - 10,282 pages
- AOL Netfind - 10,882 pages
- HotBot - 28,051 pages
- Snap - 220,320 documents
So you should always remember to use several different search engines if you don't find exactly what you are looking for with the first one you try.

Obviously if a search engine returns several thousand Web pages which contain your search keyword, then you often will have to narrow down your search. Exactly how you do this depends on which search engine you are using, as they all work a little bit differently. For example, you can narrow your searches with Infoseek as follows:

-------- A Search For Return Pages Containing ------------------------------

late deafened
"late" and/or "deafened",
preferring pages with the phrase "late deafened"
"late deafened"
the word "late" next to the word "deafened"
+late deafened "late", maybe "deafened"
+late +deafened
both "late" and "deafened" in the document, although not necessarily next to one another -late +deafened
document must contain the word "deafened" and must not contain the word "late"

Regardless of exactly how one works, all of the search engines allow a user to begin with broad searches and then narrow the focus, or to begin with very specific and detailed search instructions.

The question can always be asked "What relevance is the Web to people who are deaf or hard of hearing?" Why should we be concerned about that virtual piece of cyberspace? The answer, as has previously been indicated, is because the Web is really a mega-library of information -- information about anything and everything, including hearing loss. Attention will now be given to highlighting just a small sampling of the kinds of information that you can find on the Web potentially related to hearing loss.
You want to read the Federal Register?


You want to check out what is on ABLEDATA?

ABLEDATA is an electronic database of information on assistive technology and rehabilitation equipment available in the United States. With more than 23,000 product listings, ABLEDATA covers everything from white canes and adaptive clothing to low vision reading systems and voice output programs. Each product record provides a detailed description of the item, complete company contact information, and distributor listings (where applicable). In addition to commercially available products, the database also lists non-commercial prototypes, customized products, and one-of-a-kind products. Most of the information in ABLEDATA concerns technology for people with mobility impairments, but there are also many things there for people who have hearing loss. You might want to look at that site some day (http://www.abledata.com).

You want to browse the Program Directory of the National Institute on Disability and Rehabilitation Research (NIDRR), or look up something in Disability Statistics Abstracts?


You want to find a deaf pen pal?

One of the nice things about ALDA, of course, has always been that section of the ALDA News where you can get pen pals, where you can find a person that you can write to and enjoy conversation about your mutual experiences. Well, there are all kinds of places to find deaf pen pals, and Deaf World's Web site gives you a variety of people who are looking for pen pals (http://dww.deafworldweb.org/cgi-bin/ad/viewad.cgi).

You want to find out about deaf LISTSERV discussion forums?


If you are interested in a motion picture access project, remember that under the ADA motion picture theaters were not required to put in captioning systems. It was a kind of compromise of that legislation. But now there is technology that is being developed to allow us to go into movie theaters and enjoy first run movies as well as hearing people. Most of that technology has been experienced with and evaluated by station WGBH in Boston.
That is Larry Goldberg's operation. If you are interested in what is the status of the motion picture project, you can go to their Web site (http://www.wgbh.org/wgbh/access/) and learn about it.

All of us know about the University of Arkansas Rehabilitation Research and Training Center (RRTC) for Persons who are Deaf or Hard of Hearing. If you want a list of their publications or you want to read about their various research projects, you can do that by opening their Web site, which is found at http://www.uark.edu/depts/rehabres/.

If you make videos for one reason or another, such as a small training video, when you get all done you may want to have captions added. But what if you don't have the slightest idea of where to go or how to find somebody who will add captions to videos? You can find that information on the Web by going to the homepage of CCmaker which is located at http://www.ccmaker.com/.

If you like to ski, either downhill or cross-country, and you are deaf, you might be interested in knowing if there are any organizations for deaf skiers. Can you find that information on the Web? Certainly. Go to http://www.teleport.com/%7Eeinqham/usdsa/skilclubs.htm on the Web, and you'll find a list of ski clubs in the United States for people who are deaf.


If you don't think that the deaf and hard of hearing population is getting enough money from the United States Congress for research or training purposes, and you want to contact a member of the Senate Appropriations Committee and complain, you need to know who is on that committee. But what if you don't know? You can go to the Web and find that and other related kinds of information on the U.S. Senate Web site at http://www.senate.gov/committee/appropriations.html.

There are millions of Americans who use hearing aids. Everyone knows that one of the potential problems with hearing aid technology is humidity. Where can a person get a dehumidifier specifically made for drying out hearing aids? No, don't use a hair dryer! Rather, if you need a dehumidifier for your hearing aid you can go to the Web site of the Right Company at http://www.voicenet.com/~dryright/ and order their DryRight Hearing Aid Dehumidifier System.

How can you get a hearing dog if you live in England? Can you find that information on the Web? Sure. This is included simply because it's an example of the international features of the Web. There are a lot of Web sites in England, but if you needed a hearing dog while you were there you might look at http://www.hearing-dogs.co.uk/ which is the Web site of the Hearing Dogs for Deaf People Training Centre.
Let's assume you have recently been told that you have tinnitus. You heard mention of the neurophysiological model of tinnitus, but you don't know what that is all about. You can learn all you will ever want to learn about tinnitus by visiting the Web site of the Tinnitus & Hyperacusis Center at the University of Maryland at Baltimore: http://www.tinnitus-pjj.com/.

Maybe you want to find out more about the mission of Self Help for Hard of Hearing People (SHHH) in order to decide if you would like to join that organization. You can read the SHHH mission statement at http://www.shhh.org/newdocs/mission.htm. Or maybe you have a need to know who's on the Board of the National Association of the Deaf (NAD). You could find that out by looking at http://www.nad.org/Board.html.

The National Information Center on Deafness (NICD) is located at Gallaudet University. Maybe you want to get a copy of their publication "Late Deafened Adults: A Selected Annotated Bibliography" but don't know how to order it. Go to their Web at http://www.gallaudet.edu/~nicd/ and you will find the information you need.

Do you need to order a new visual smoke detector or a new text telephone (TTY) for people who are deaf? You can go to the Web site of Nationwide Flashing Signal Systems, Inc. (NFSS) at http://www.nfss.com/ and place your order on-line. Or if you are a comparative shopper, you might also want to visit the Web site of Harris Communications at http://www.harriscomm.com/ to see if their prices are cheaper.

Maybe you want to read the Deaf Digest and keep up with news affecting people who are deaf or hard of hearing. You can read the Deaf Digest on-line at http://www.yellowstar.com/DeafDigest/homeframe.htm.

If you are interested in getting a copy of a captioned film or video to watch with a group of deaf or hard of hearing friends, you may find just what you are looking for at the Web site of the Captioned Films and Videos (CFV) program: http://www.cfv.org/. The United States government funds the CFV program which is run by the National Association of the Deaf.

Suppose you are visiting in Washington, DC and you need to locate an otolaryngologist (ENT) but you don't have a telephone book handy. You can get a list of hearing care professionals in the city of your choice from the Web site of the Better Hearing Institute: http://www.betterhearing.org/provider.htm.

The list of examples could go on and on, but hopefully the point is clear. There are a great many Web sites of potential interest or benefit to people who are deaf or hard of hearing. In fact, some Web sites are primarily dedicated to providing links to other sites related to hearing loss. Three such sites include:

- Dr. Dave's Deaf and HOH Web Links→http://members.aol.com/DrDaveLink/links.htm
- Deaf Linx → http://www.geocities.com/CollegePark/Quad/9220/
- Deaf Resource Library → http://www.deaflibrary.org/
If you open any of these sites you will find a long list of deafness related links, which will put an entire library pertaining to hearing loss right at your fingertips.

We would be remiss if we didn’t end this paper with a brief discussion of the Web site of the Association of Late-Deafened Adults (ALDA). In general, all of the national organizations for people who are deaf or hard of hearing have Web sites. For example:

- The National Association of the Deaf (NAD) → http://www.nad.com
- Self Help for Hard of Hearing People (SHHH) → http://www.shhh.org
- Alexander Graham Bell Association for the Deaf (AGBAD) → http://www.agbell.org

The ALDA Web site is located at http://www.alda.org/ and is the newest Web site of the national organizations related to hearing loss. It contains information about the history of the organization, the Annual International Convention of ALDA (ALDAcon), and the members of the ALDA Board of Directors. In addition there are links to the home pages of several of the ALDA Chapters around the country. Stop in for a visit and learn more about the organization that provides a home to many late-deafened adults.

In closing, hopefully this paper has served to spark your interest in the World Wide Web. Indeed, it can be a tremendous information resource for people who are deaf or hard of hearing, once you learn to navigate its waters. It can provide many benefits, including social support, technical information, and endless entertainment. In addition, it can be great fun! We hope that we have given you the necessary information to get started and find what you need. If you ever have any questions about the Web, feel free to contact either of us by sending e-mail to rmiller@siu.edu (Roy Miller) or alda96ken@aol.com (Ken Arcia). Happy surfing!
HOT NEW TECHNOLOGY

Judith Harkins, Jerry Aldrich, Gary Moulton, and Mike Hoghooghi

Judy Harkins:

I want to talk to you about hot technology from some hot American companies. I have brought together a group of people from industry who are doing things to make technology more accessible. They are working within their companies to look into access problems, and to develop solutions.

If we think about the progress that has occurred in accessibility and visual communications in the past ten years it’s really quite remarkable. It has literally changed our lives, and I’m sure that as technology continues to progress, it’s going to have an even larger impact on all of us.

Many of the technologies that the deafened use are not special technologies. They are technologies that everyone uses. In fact visual communication has become every day communication for a very large part of the American public. And coming up on the horizon, we have a lot more exciting things to look forward to: like better speech recognition to translate a hearing person’s speech into text; and remote services that work like relay services for interpreting and CART, so that you can get these services wherever you are -- and not have to be in a particular place with a particular person to obtain them.

Video telecommunications is also coming on very fast, and soon we will be able to see each other as we talk, which will enhance your communication. There are many, many more technologies that are coming up -- some that we can’t even imagine, because the computer is becoming a telephone, as well as a television.

We are also fortunate to have some laws on your side with regard to accessibility, and they have been helpful in encouraging industry to do the right thing in regard to those of us with hearing loss. Just to go through quickly what some of those are--we have the ADA, which was a great help in terms of establishing telecommunications accessibility and in terms of improving public accommodation accessibility. We have the TV Decoder Circuitry Act, which has made every TV you buy an accessible TV. We have the Telecommunications Act of 1996, which we are just beginning to implement now in terms of accessibility. This requires companies that make telecommunications equipment to make it accessible to, and usable by,
people with disabilities, if it's readily achievable for the company to do. Companies are looking at their product development and seeing what they can do to improve the accessibility of the products as they develop them.

This law, as you probably know, also requires the captioning of televised video programming. We have a new rule that has just come out from the FCC on that issue.

And, finally, we have the Hearing Aid Compatibility Act, which requires hearing aid compatibility with telephones. It is this law that is now driving the interest of the FCC in terms of making the new wireless telephones more accessible.

There are challenges too. For example, we are seeing slow progress in some areas of visual (text) communication in public spaces, like airports. Another problem that we have to deal with is that the Internet and computers are beginning to talk. So there is an accessibility concern in regard to this in terms of captioning for people who are deaf and hard of hearing.

Another concern we have is with new phones, particularly some of the wireless phones that don't work with TTYs and hearing aids. Our colleague from Microsoft will be talking about captioning the Internet and other media. And our colleague from Motorola will be talking with us about this question of making phones more accessible, and also about what the new text-based services can do for you.

Our speaker from Walt Disney World will be Jerry Aldrich, who is the Director of Independence Programs. Jerry has been with Walt Disney World for 26 years, and has worked all over the world for Disney in a wide variety of capacities.

Gary Moulton, a project manager in Microsoft's marketing group, will tell us about captioning media. He is responsible for Microsoft's work with key disability organizations. He joined Microsoft in 1995. Before that, he was with Apple in the disability resources group. So Gary has been working in the area of computer access and disability for many years.

Originally, trained as a psychologist, Gary worked as a clinician in early intervention programs, in addition to teaching child growth and development at the undergraduate and graduate level, and managing a program for the integration of adults with disabilities into community living and work programs. So, he also has a long background with relation to working with disabled people directly.

Mike Hoghooghi is an engineering and business manager for the text messaging products in Motorola's North America paging subscriber division. He has held a lot of different positions at Motorola -- from design engineering to business management and domestic permanent international wireless markets. The last four
years he has been focusing on text messaging products which are of great interest to those of you who use pagers.

Jerry Aldrich:

I'm Jerry Aldrich from Walt Disney World. I've been with Disney for 26 years, coming from the aerospace industry. I started in the audio electronics areas in maintenance and engineering, and then when the Epcot project came along in the early '80s, I was involved with the electronic systems and the communication systems that we use at Epcot.

Most recently I was the Director of Independence Programs, where we worked at making our parks more accessible for everyone. We would like it to be as accessible as possible, and some of the technology that we have today makes that possible. Today things are changing rapidly -- almost weekly. We presently have 50 venues equipped with assistive listening systems that we hope are compatible with the needs of those who use them. They are Audex in the majority of the cases.

The fixed-seating theater, as well as stand-up theater, type attractions have assistive listening systems. Also, all pre-show areas in our theaters, where instructions are given for the show, have assistive listening systems.

Research continues for suitable devices that can be adapted for slow-moving ride attractions in our parks. The show synchronization for these rides is a problem that does not come with an easy solution. In addition to remaining in sync with the ride, the device must be of such a design that it does not inadvertently become a projectile endangering the guests on the ride vehicle.

On the "Galaxy Search Theater" in "Tomorrow Land" at the Magic Kingdom, we use an infrared system which works well in this theater. Even though this is an outdoor venue, sun shades provide enough protection from the ultraviolet rays that the captions remain visible. We have also taken, in the last few months, some bench seating away in the front of this theater to provide room for wheelchairs or other special adaptive equipment that disabled visitors might need.

We are also working on video closed captioning. We developed a guest-activated closed captioning system for use in selected video monitors. A guest, who is required to leave a refundable deposit, can receive a button captioning device which activates captions. For example, in the pre-show or gathering areas, where we use video to present the material on multiple monitors, at least one monitor has closed captioning. There will be a visible black and white CC symbol displayed at the bottom of the monitor so it can be activated by the guest. There will be about 33 different attractions that have this video captioning when we are completed.
This is an example of the guest activator. Our goal is to have a device that will operate reliably, that is convenient to carry around and is simple to operate. All of our video media is stored on videodisc at the present time. As technology moves on, it's a good story, bad story type thing. Today we are looking for new technology, which will no longer use videodisc machines, and be accessible for everyone for our new park "Animal Kingdom," which opens in May.

We are aware too that as high definition television comes along, there are a lot of people working on format, but that there is more work being done on format for broadcast television than there is for stored television, like we are doing. So, as we are into some of the digital storage devices, we have to work on a format to make sure we keep captioning available and the stream of data that is coming off.

In the theater-type attractions, where the production is primarily presented through motion picture film or large screen video, we have opted to incorporate the reflective captioning after positive comments at the SHHH conventions. We use a Rear Window system developed by WGBH and invented by Rufus Butler Seder. The system provides captioning that can be viewed on an acrylic panel connected to a microphone stand, which is placed between the guest and the presentation. In this method captioning is presented on an LED sign in reverse image in sync with the show material. The sign is mounted near the rear of the theater. The reflective captioning is only illuminated upon a guest's request for the system at the attraction. The attractions that have the reflective captioning are indicated on a guest map that is readily available.

Walt Disney World also makes interpreting services available at the Magic Kingdom, Epcot and MGM on a rotating basis so the guests know precisely when the services are available at the specific parks. The schedule alternates between each of the parks. And one performance at each identified live show is done on every day.

This has been done daily for over a year now. We started October 1, 1996. And as a performer moves around an attraction, the interpreter continues to translate for the guest. Because our entertainment schedule changes all the time, you need to stop by the Guest Relations area to pick up a schedule for that day.

We are installing TTYs in strategic locations in our parks at the public telephone locations. There are four or five locations per park in both employee and guest areas. We have just recently authorized the installation of even more. I believe there are about 45 installed now on the property.

In all of these things, of course, we are talking about high-tech systems. I know a lot of you all use the Internet. Before you visit one of our parks, I really suggest that you visit www.disney.com. There is a page in there which is for the disabled. It lists
all of the services which are available. They change a lot as we move along, and it is good to make sure you have the latest information before you visit us.

The last, and most challenging thing that we need to work on, isn’t high tech, but it is probably the most important of all. That is the training of our employees - both in terms of sensitivity training, and technically so that they know about the equipment and how it operates. We at Disney have spent millions of dollars installing systems, and we try very hard to make our employees realize all the systems are there so you can enjoy your day at the park more. I would like to encourage you to stop by the guest relations area, test us, and help us to improve our services to those who have a hearing loss.

Our next speaker will be Mike Hoghooghi from Motorola. He will be talking about the wireless future.

Mike Hoghooghi:

Good morning. My name is Mike Hoghooghi. I'm with the paging division in Motorola. I've been with Motorola about 12 years in different capacities.

I want to tell you about some of our efforts at Motorola, in terms of both our products, and in terms of what we are doing in response to access issues. We have a great many solutions for the hearing-impaired.

First, I want to talk about wireless technology. Motorola's vision of wireless communication covers the needs of our whole population: the able bodied and the disabled. Today, paging and the cellular devices, PCS, analog telephones, basically lead the wireless way in terms of communication. They are being used for personal messaging, business communication, and information and content type services. Basically, we are providing specific information that is of specific interest to individuals.

The good thing about our business is that the market has a great potential for growth, and is evolving into something that provides real solutions for the whole population in terms of communication -- not just domestically, but internationally. And we are in a position now where we can improve both the products and the services based on feedback and consumer needs, as technology evolves. Both products and services are growing rapidly -- almost on a daily basis -- thus, increasing the utility of such useful devices as pagers and cellular phones.

There are a great many factors that are affecting the industry in a very positive way. Among them, as Judy mentioned, Section 255 of the Telecommunications Act of 1996. There is also a lot of effort that is going on both in the regulatory agencies as well as in the industry itself. Thus, there is a lot of market expansion because of
these factors and because of the growth of the wireless and the wireless mind set. The opportunities that I'm talking about are primarily for the folks that would be benefitting from the access legislation, and it's really not just about the hearing-impaired, it's about their families and friends too.

So our goal is to keep the devices as non-intrusive as possible, so that we do not advertise that there is an impairment, but rather offer a solution to the individual who needs the service or benefit of that technology.

Paging has a great many solutions for the hearing-impaired. We were one of the first companies, if not the first company, to have a Silent Advisor, which basically was a text message display, four lines. This tailored a lot of its features to the hearing-impaired.

I understand that Motorola's watch pager is of great interest to many people with a hearing loss, and we support that by continuing to market a watch pager. There is a new one that we did jointly with Timex, so we synergized with a watch company that had great expertise in that area and improved on this product in a very real way.

We have a few more alpha entry devices that look like TTYs. The benefits of these is that they make access to the paging service provider easier and more economical. This ensures that messages can be directly dispatched by yourself or by the folks who want to communicate with you.

Some of the databases we are using are from the National Center for Health Statistics and the Census Bureau. They have great information on disabilities that we use to provide better service and products for the disabled community. We always try to collaborate with outside experts in this way. We have been working with some of the leaders in TTY/TDD development, for example. All this information is helpful to us in mapping the needs of all disabled individuals with impairments of all types.

The old traditional methods of product development is our linchpin for improving our access and telecommunication quality for people with disabilities. The first step is to evaluate the need and relevance for access. In terms of a matrix of products and services, we're also helping our partners -- that is the service providers, for Motorola is not itself a service provider -- to get up to speed and make the services available more economical for you. We have training plans to get engineering, marketing and support service people to understand special needs, as well as the communication channels so we can get feedback from the disabled themselves.

Then, too, we need to qualify products against established guidelines. Again, FCC adoption or creation of validation processes, will help Motorola and the industry in
doing this. I know Motorola is involved with that as well as disabled persons themselves.

So the end goal is to have tailored and specific solutions for specific categories of people with disabilities. Again, it doesn't necessarily just end with the hearing-impaired, even though we feel a little stronger about helping those with hearing loss because our company is dealing with communication. But ultimately we want to develop solutions for all disabilities.

It's too early to start talking in terms of specific features and general scenarios. But one thing that is helping us right now is the fact that Motorola is closely involved with Judy's organization, Gallaudet University, as well as some of the research that we are doing with Disney. Some of the other industry leaders are also paying attention to these areas.

The access requirements, and meeting those requirements, is an ongoing process, and we hope to work very closely with the disabled in order to have your feedback flow into Motorola. I encourage you to get us the information, whether it's through the web site at www.mot.com, or the representatives that we already have in place to give us the feedback that we need to provide better service and better products for everyone.

**Audience Member:**

My question is: What is Motorola doing to insure the availability of this technology at the consumer level? The reason I'm saying this is two life experiences. Number one, about a year ago I attended a trade show sponsored and put on by Motorola. I went up to one of their representatives, one of the people who was in charge and I said, "Please tell me about products, text based products, that are applicable to the deaf and hard-of-hearing." And he said, "Huh?"

Second, I'm in the process of switching over my commission's contract for paging services. Although all of the qualified vendors provide Motorola alphanumeric pagers, Advisor, SilentAdvisor, et cetera, not one of them is offering TTY message entry as an option. The only option for deaf and hard of hearing people is to go through the paging service's voice operator, paying a lot more money per message than they have to. So, again my question to you is: What is Motorola doing in terms of its corporate commitment to insure that in the real world this access and this technology is pragmatically and realistically available to consumers?

**Mike Hoghooghi:**

Thank you. That's a great question. That is one of the things that we are working on right now, and you're absolutely right, we don't have a good solution right now. We
have acknowledged that. We are working on getting our carriers with TTYs into the paging terminals and getting direct dispatch. The reason that the TTY direct dispatch is not fully supported by every single carrier across the country, is that it tends to be the least cost-effective way of getting the message into the terminal from a service provider’s point of view.

One of the things that Motorola is doing is, in addition to increasing sensitivity awareness — whether to the carrier community or Motorola sales community — is to put products in our road map, of which we have a couple right now, that combines TTY or TDD capability with AED (Alpha Entry Devices) dispatch capability. That makes it more economical to get the message to the terminal from a carrier perspective. It provides the same platform that you are using today to get the message and use it as you use the TDDs or TTYs.

Audience Member:

That works very well for an entity with a fixed location who is sending a large number of pages out, but what I’m talking about are individual messages -- for example, hearing spouses who may want to reach deaf spouses or significant others. Can the deaf spouse use that TTY pay phone to send an alpha page to the spouse? I mean, if you are talking non-cost-effective, there is hardly anything that is as non-cost-effective as a voice-operator-mediated page. There are also companies that could become service partners to the retailers of Motorola paging services that would provide the TTY capabilities and the radio Towers.

If you, Motorola, the provider and manufacturer of the pagers, emphasized the importance both for legal compliance and for ethical fairness, you could really help change society and make life a lot easier for everybody in this room.

Mike Hoghooghi:

I agree. And when I said cost effectiveness, it was in reference to the carrier or service provider view, and I did not mean to generalize that. I was trying to address the fact that there are technical solutions for us to get rid of the cost ineffectiveness or the access issues. It doesn't have to be like this. That is basically what we are working on.

Right now, even for people without disabilities, if you will, for folks that can get their messages and talk to a voice operator at the carrier site, that is not really the perfect model either. Right now, that is a significant portion of the carrier fixed costs. So, having direct dispatch products at the user level, it helps the carrier, it helps individuals at all levels with or without disabilities. And that’s one of the messages that we are trying to put forward in the industry, not just in paging. Because the devices will also work for the new telephones that have short messaging service
J. Harkins, J. Aldrich, G. Moulton, & M. Hoghooghi

capabilities called SMS. You can use the same device to send the message to
either a pager or cell phone at that point.

Gary Moulton:

My name is Gary Moulton. I'm a product manager in Microsoft's Personal and
Business Systems Group. That is the group that is responsible for the operating
system side of the house. So if you are familiar with DOS and Windows 3.1, and
Windows '95, and Windows NT, and Windows '98, that is the stuff that I work on,
specifically from the side of access.

Those of you that are familiar with those operating systems know that there are
built-in utilities that were put there specifically for individuals with disabilities. We are
continuing to evolve those products, specifically the operating systems, so that they
are even more accessible to you.

Specifically, when Windows '98 comes out next year, in addition to the accessibility
options that were there since the product was introduced in Windows '95, there will
be some additional access features as well. For example, there will be an
accessibility setting that enables a person when they sign-on to Windows '98 to
configure their computer to their individual needs.

In addition to the accessibility settings, there will be a screen magnifier as part of
Windows '98. As the operating systems evolve, those features will evolve along with
them and there will be additional features put into the operating system.

I'm also part of a larger group at Microsoft: the Accessibility and Disabilities Group.
This group is made up of about eight full time folks scattered across the company.
Not only does Microsoft manufacture operating systems, but we have a fair number
of products as well. Through this group we have been able to make many
advances. For example, our new electronic encyclopedia Encarta, which was just
released this year is fully captioned. So there was a person working on that project
to make sure that product was accessible. In addition, we have folks that are
working in other groups at Microsoft as well, and make sure that our products,
programs and services are as accessible as possible.

The foundation for that comes in a corporate policy statement that Bill Gates signed.
It says: "It's incumbent upon every Microsoft employee to insure the product,
programs and services are accessible to individuals with disabilities." It's every
employee's responsibility at Microsoft to ensure that happens. At our website,
www.microsoft.com/enable, you can get product information about Microsoft's
products that are accessible to individuals with disabilities, as well as information
about third-party products that make our operating systems or applications
accessible. So that is kind of a general overview of what we are doing. Let me put
this into perspective, because I want to talk about multimedia today, and address it from the standpoint of three "givens" specifically in relation to the personal computer industry and software. The first given is that nothing new ever works. Now, you might say why do I say that, being a person from Microsoft, touting technology, who is supposed to be an evangelist of software. Well, there are three reasons that it is fairly easy to say that nothing new works. First of all, it's not easy. In spite of what we say about technology, it is not easy for an individual to use technology.

For example, the computer that I'm using right now took me about five minutes to figure out how to open it up. It's not my computer. I couldn't figure out how to open it up so that I could see the screen. So, technology is not easy. Spoons are easy. Technology is not.

The second given in terms of personal computer technology, and technology in general, is that you can automatically say that not everyone can use what is new. It's fairly easy as a person in the Accessibility and Disability Group at Microsoft to say that. When you come out with the latest and greatest technology, typically you can find one person somewhere in the world who can't use that technology. Chances are too that person is going to call you the day after the product is launched and announced.

The second thing is, most companies don't understand accessibility disability. If they do understand it, chances are they look at it in terms of charity or poster children as opposed to discriminating consumers. So, the whole idea of making technology accessible because you have discriminating consumers is something that doesn't typically come to mind to corporations.

Then the third category here, that I think is important to understand is that we are always, within technology, as far as accessibility and disability is concerned, looking for that single magical one line of code. The nearest example I can get to this is automatic teller machines. Some of these machines are designed so that you have to remove your card, your ATM card, before you get your money. That is a wonderful example that the person who designed that system understood human nature, that the first response that anyone is going to have in using an ATM is they are going to take their money and run. But if you leave the card there, it is going to cause problems. But if you have to remove that plastic card before you get your money, chances are you're going to lose a lot less cards. So it's an indication that the person who designed that system fundamentally understood human nature.

With that perspective in mind, look at the fact that Microsoft is consciously trying to understand what it means, fundamentally means, to make our products, programs and services accessible to individuals with disability. And trying to find that one magical line of code, that will make our products, programs, and services show that
we really understand what is needed. So what I want to talk about today is the technology we have developed to make multimedia accessible.

Multimedia has been around for a number of years. In fact, I was at Apple during the first swell of interest in multimedia. Then it was: If you put CD-ROM drives in a personal computer, we are going to be able to take advantage of this tremendous capability that is called CD. Now, over the last ten years or so since, that has happened. CDs are primarily used for storage of large quantities of data and audio as well. But we have never really seen the benefit of multimedia because of that installation of technology in a personal computer. Now, with the Internet, multimedia in a sense has gotten new life.

So there is an opportunity to put video and audio on the Internet and really use the Internet to disseminate this technology and enable folks to use it relatively easily. The problem is again, whenever you use anything new, at first it’s not going to work. There are going to be problems. There will be technical problems: bandwidth problems they are talking about, or it will crash your system, or you don’t have the right setup to be able to use it on your computer. But the primary problem is that not everyone is going to be able to take advantage of that particular technology.

Now, the most relevant thing here is the fact that we have multimedia out on the Internet that is not accessible to individuals with disabilities, specifically individuals who are hearing-impaired, hard of hearing, deaf, individuals who are blind or visually-impaired. So what Microsoft has done is to develop this tool called SAMI, Synchronized Accessible Media Interface. I’ll not go into the technical details of this, but this is, hopefully, the one line of magical code that we can give to software manufacturers, to folks who disseminate their information out on the Internet, and say if you want to make your products, programs and services accessible to everyone, all you have to do is include this particular technology in your product. You give it away free. In a sense, you make it a standard in terms of having it out there for folks to be able to utilize.

Now, the benefit of that technology is the fact that if we make it easy for, say, individuals who are hard of hearing or deaf, to be able to use the Internet, we have automatically made it a lot easier for everyone to be able to use that technology. The additional benefit of SAMI, that we didn’t know when we first designed this particular tool kit, is that individuals who are visually-impaired can also benefit from this technology as well. Because not only is it a tool for providing captioning of video images, it is also a tool for integrating an audio and specifically an audio description, into a video track, which is relevant to individuals who are visually-impaired or blind.

All of you, I am sure, are familiar with the reasons for closed captioning, but when we first started all of this was fairly new to us at Microsoft. But as we went along we found that even though we were trying to make the products more accessible for
individuals who are hearing-impaired or deaf, we found there were additional benefits as well.

For example, I call your attention to multimedia noise in a classroom situation. If you have a lot of computers in a classroom, all of which are making sounds, it can create chaos in the classroom. But with captioning a possibility, you can turn the sound off, and have the students read the captioning. Also, noisy environments in factories, poor audio quality are also situations where captioning can be of benefit.

All of you have seen a broadcast from space. They are showing, you know, the astronauts floating in space and the capsules and everything. And you never can understand one word of what they are saying. But with SAMI, we can all actually understand what is being said. So something that provides access to an individual with a disability can also have benefits to us all as well. The other advantage of SAMI is the fact that we are able to customize the captioning to the specific individual with a disability. So, for example, if particular captioning is too small for a person it can be changed easily and made larger.

Another example of what you can do with SAMI -- and when I say "you," I really mean YOU! Typically, when somebody from Microsoft says "you," they are talking about a programmer or developer, but here I am talking about a typical user. Now what SAMI allows us to do is to overlay additional components, not only text or captioning, and to modify what is shown to make it easy to use -- for example, highlighting of the text following the spoken words. So somebody that is having difficulty following the captioning or having difficulty reading, this would be an aid for them. You are also able to add additional picture cues and graphic cues to the text as well.

The other advantage of SAMI is the fact that not only can you have the English text, but you can easily translate it without going back through and remastering the entire thing. You simply install an additional file.

I want to make one final point, and this is the fact that multimedia technology is something that is getting a lot of hype. Everyone is talking about multimedia. This is fantastic technology. This is something that can invigorate the use of the Internet. But unless the technology is easy to use, unless everyone can use it and unless we can use our advantages with this technology to add additional components, things that we never would have imagined, we are not truly taking advantage of the benefit of technology. And I think SAMI is a step in the right direction. Our ability and desire to make our products, programs and services accessible to individuals with disabilities will automatically make technology more accessible and easier to use for everybody.
Two additional comments: First to use SAMI for the first time all you have to know is a good HTML editor. It's as simple as that. So for the first time, a person who can use a text editor, any good text editor, would be able to use SAMI. That's all a SAMI file is. Second, SAMI can be downloaded at the Microsoft website.
HEARING TECHNOLOGY RESEARCH AND ACCESSIBILITY:
DISCUSSION AND DIALOGUE

Matthew H. Bakke and Anita B. Haravon

Anita Haravon:

The Lexington School for the Deaf/ Lexington Center for the Deaf in New York City is comprised of the School for the Deaf, Vocational Services Center, Mental Health Center, Hearing and Speech Center and Research Division. The Research Division was awarded a grant from the National Institute on Disability and Rehabilitation Research (NIDRR), U.S. Dept. of Education, called the Rehabilitation Engineering Research Center (RERC) on Hearing Enhancement and Assistive Devices. The RERC was established by NIDRR to promote technological solutions to problems confronting deaf and hard of hearing people, to develop systems for the exchange of information about Assistive technology, and to improve the distribution of Assistive devices. We strive to meet these objectives by developing and evaluating cost effective technologies for people with hearing loss and by educating consumers about solutions that are already available. We collaborate with Judy Harkins, Ph.D., the director of the RERC on Universal Telecommunications Access at Gallaudet University.

Highlights of our research projects:

- Early Detection Of Hearing Loss
- FM Hearing Aids
- Remote Computer-Assisted Realtime Transcription (CART)
- Telecommunications Access.

Early Detection Of Hearing Loss

Matthew Bakke:

You might ask why should you be interested in early detection of hearing loss in young children. Well, perhaps it is not something that you would be interested in personally for yourself, but certainly it is an important issue in deafness. It is very important that children be identified as being deaf or hard of hearing early in life. Some of you may have been hard of hearing before you became deaf. As a young child, it is very important to get certain kinds of help. For example, hearing aids, very early on, auditory training, and if a child is deaf, of course, it is very important for the
parents to begin the process of deciding how to deal with hearing loss. Will my child use sign language? Will my child use a hearing aid? Will my child use a cochlear implant? What kinds of educational options are available? The earlier that we know about the deafness, the earlier we can begin to work with families to make informed decisions.

The goal of the project is a fast and efficient screening of infants for hearing loss. This is a cooperative project of our RERC, and two private companies, Etymotic Company and Mimosa Acoustics, which are based in New Jersey. We want to be able to test very young babies in order to identify children who may need further testing and those who you can be pretty sure have healthy ears.

The screening tool uses something that we call Otoacoustic Emissions. Oto, refers to ear, and acoustic means sound. These are the emissions or sounds coming out of the ear as opposed to the sounds going into the ear. It was 15 or 20 years ago that scientists discovered that ears make sound as well as receive sound. The sounds that the ear makes can be useful in diagnosing hearing loss.

To measure emissions, you put a probe or little earpiece into the person's ear, and you present two different tones--two different beeps, which are slightly different in frequency. When those sounds go into the ear, they interact and create what is called a distortion. It is similar to the kind of distortion you would get in a cheap radio. Distortion means that sounds may come out of the sound system that you did not put in. So if you have a cheap radio you may hear "junk" coming out of it. That "junk" is called distortion.

The ear can also produce distortion. So a healthy ear produces a third tone, which is a distortion or an emission. We can detect that distortion with very sensitive microphones and signal processing. If you see there is an emission, then you know that there is not a significant hearing loss. You know that the ear is healthy. If there is no emission, then you know that there is a hearing loss. (See Figure 1).

Audience:

So this test is really not sensitive for more minor hearing losses?

Matthew Bakke:

No. It is sensitive to more severe hearing loss, and it is really a screening tool, not a substitute for an audiogram. If you see that a child or a person has no emissions, that means you need to do further testing. If you see that they do have emissions, because the emissions may be large or small, it does give you an indication that there might be a mild hearing loss, but you really have to do further audiometric testing to know that.
An Otoacoustic Emissions Measurement

1. Probes (2 tones) put in the ear
2. The healthy ear will produce a third tone (emission)
3. Significant hearing loss (<50db), NO EMISSION

Ear Plug

Frequency #1
Emission ???
Frequency #2

Ear Drum
Audience:

Is it standard to do it?

Matthew Bakke:

It is not standard yet, and it would not be done in isolation. We hope that, eventually, it will be part of a battery of tests for newborns.

Audience:

Can this tool be used for both conductive and sensorineural hearing losses?

Matthew Bakke:

The test can determine if there is a hearing loss, but you have to do other tests to find out if it is a conductive loss rather than a sensory loss. However, the next step in our development of this tool is to build into the system a test that checks for conductive loss. You would put the probe in and it would do a test called impedance. The impedance test would tell you right away if this is an ear that has a conductive problem. If it is an ear with a conductive problem, then you need to clear up that problem before you do the test for sensory hearing loss.

Another new development is the Behind-the-Ear (BTE) FM Hearing Aids for Profoundly Deaf People. This is for people that can benefit from hearing Aids and features an FM or an infrared system which can be extremely helpful because it moves the microphone close to the talker and reduces the effects of background noise and reverberation. We are interested in new hearing aid technology that has FM receivers built right into the aid. Two companies, AVR and Phonic Ear currently manufacture BTE-FM Hearing Aids. This means that you don't need an extra box. The hearing aid itself receives the FM signal. There is a transmitter with a microphone that is held by the speaker. The speaker gets close to the microphone so you can hear his voice clearly and other background noise is not heard. (See Figure 2).

Audience:

How much do these new hearing aids cost?

Matthew Bakke:

About $1,500. The newer technology hearing aids tend to be higher in cost than the analog or "regular" hearing aids.
Figure 2

FM Listening Systems

Transmitter:
microphone held by the speaker

Receiver
(for the listener)

Radio Signal
Audience:

I use an assistive listening device. Comtek, I think, with the transmitter and FM receiver. If I go to a lecture or a concert and they are not broadcasting on the same frequency as my receiver, then I can't receive it. I am trying to understand how this hearing aid works and if it can receive different frequencies.

Matthew Bakke:

One of the problems with FM is that they do broadcast on different frequencies. The reason that they do that is because of the problem of spillover. You might have two different lectures or classrooms with meetings going on at the same time, and you don't want the transmission from one meeting to go into the other meeting, so you operate on a different FM frequency. The receiver that comes with the behind-the-ear FM system is tuned to a given frequency, and that frequency would go with its transmitter. So you really need to use your own transmitter with the BTE-FM behind-the-ear hearing aid.

The RERC is involved in a project with the manufacturers of FM systems, infrared systems, movie theater owners, live theater owners and people who install these kinds of devices in public places, to come up with some kinds of standards that will help alleviate that kind of problem. The Federal Access Board has funded this work. With the BTE-FM hearing aid, you would wear this hearing aid and then you would have a transmitter which you could give to anyone. Let's say you are at a dinner, and it is in a noisy restaurant and you want to talk to a person at the table. You give the person a microphone, and they put the microphone close to their mouth. You get that signal clearly without all the noise. The downside is that it only has one microphone so you can only talk to one person at a time. If you are with a group, people have to behave themselves and only talk in their turn and always pass the microphone.

The advantages of the FM systems also apply to infrared and loop systems. You reduce the background noise. You reduce the effects of room reverberation, i.e., the echoes in the room that interfere with your understanding of speech. You will notice that in some rooms it is easier to understand speech than others. For example, if you go into St. Patrick's Cathedral in New York and try to talk to somebody, forget it. There is incredible reverberation because of the enormous space. This is why in many cases when you go to the audiologist and you try out your new hearing aid it sounds so clear. But then when you walk out into a real room, it doesn't sound as clear. That is the problem of room reverberation. The other advantage of FM is it keeps the talker's voice at a relatively constant level for you so it doesn't disappear and come back.
Audience:

I thought that distance would cause distortion. If you get more than a couple feet away from the sound source, you get distortion. A lot of people try to put the microphone in the middle of a table so people don't have to pass it around, but you really lose a lot of the effect by being that far away from the microphone. The speech is not as clear.

Matthew Bakke:

That's correct. The microphone distance is critical. It's not really that it is distortion as much as two other things. One is the fact that the sound of a voice becomes less intense as you go away from the microphone and, therefore, the background noise relative to the voice increases, so your signal and noise get mixed together. The other problem is the reverberation in the room. The farther you are from the microphone, the more chance that the sound from the voice to the microphone is not going to be as strong as the reflected sound in the room. The reflected sound in the room tends to confuse the signal, so it is critical to be close to the microphone.

At RERC we ask the research question: how does the BTE-FM compare to the more traditional body worn FM? Basically we found that they worked as well as body worn FMs. They did provide a significant advantage for students at the Clarke School for the Deaf in North Hampton, Massachusetts. There was a slight problem for some of the more profoundly deaf students in that the BTE-FM hearing aids use a different kind of limiting, than do regular hearing aids. The BTE-FM aid uses a way of compressing the sound so that when it becomes too loud, it is limited in a soft way, whereas the students were used to more of a hard way of keeping the sound down. So there has to be some adjustment made for that problem. Our next step is to do more evaluations of these with adult populations.

Audience:

For people who use the FM system with a neck loop, would that work with the behind-the-ear FM?

Matthew Bakke:

Good question. Okay. Theoretically, it would not be necessary to use the neck loop because the FM would be received right by the hearing aid itself eliminating the necessity for the neck loop. However, let’s suppose you are in a situation where the transmitting frequency is different. You might opt to use a neck loop and switch to the telecoil setting.
In the case of both FM and infrared transmissions, do you know whether cochlear implants can be set to receive those signals instead of a usual microphone reception?

Matthew Bakke:

Yes. Some of the assistive listening device and cochlear implant companies, have made special patch cords to connect the cochlear implant with FM and Infrared Receivers.

Anita Haravon:

We are going to switch gears and talk about remote computer-assisted transcription (CART). The CART reporter would not have to be in the room with us, but could be at some other location, maybe across the country, and would be listening to the meeting over the phone. This would be cost effective because the reporter wouldn’t have to come to the meeting. At the meeting, there would be a phone, a modem and a laptop computer. The deaf or hard of hearing person would read from the laptop computer at the table, and there would be a microphone connected to the telephone. There would be one phone line for the reporter to be listening to the meeting and then over another phone line the text would be sent to the modem and onto the computer screen. (See Figures 3 and 4).

Audience:

Wouldn’t Simply Speaking, IBM’s speech recognition system, be a lot simpler and a lot cheaper than what you are talking about?

Anita Haravon:

The question is about computer speech recognition. IBM and other companies are coming out with software that can change speech into text automatically using a computer with no human interface. That software exists today, but there are some problems with it. You need to train the computer to understand your voice and then it is pretty accurate. You need to speak one word at a time because the computer doesn’t know where a word begins and ends. They are coming out now with improved software, but for today a computer would not be a reliable CART reporter.

Audience:

This makes me think of using a relay service, an operator, as a kind of transcriber.
Figure 3

Basic Requirements for Remote CART

- Speakerphone
- Modem
- Phone line for transcriber to listen
- 2nd phone line for text to be sent
- Computer
- Transcriber
Figure 4
RERC Work on Remote CART

- Improving microphone quality
- Evaluating voice + data modems (to permit one phone line)
- New software for user control
- Field Tests

computer

transcriber
Anita Haravon:

Yes. The CART reporter would be like a highly trained relay operator. One of the biggest problems is that voice quality on the phone is not great. What if the CART reporter can’t understand what a person said? We are working on improving microphone quality to make sure that the reporter can hear accurately what is being said during a meeting. We have recently received a three year grant to work specifically on improving the quality of directional microphones.

We are also looking into voice/data modems, meaning modems that can receive both voice and data information. This would allow us to use only one phone line for both voice and text. Judy Harkins at Gallaudet is working on improving the laptop itself, i.e., designing a laptop that allows for more user control. For example, the ability to increase the font and text size.

Telecommunications: Wireless (Cellular) Phones

A quote from Consumer Reports: "Cell phones have taken off faster than fax machines, faster than cable TV, and just as fast as the ubiquitous VCR (Consumer Reports, February 1997)." So cell phones are in our life, and probably, soon, we will all own one. In the future the wireless phone and the computer are all going to be one device that we will carry with us everywhere. We will be able to use it for paging, faxing, e-mail (electronic mail), and even Internet browsing. It is going to be a mobile or wireless phone or a fixed phone in your house. Today the industry is starting to call this personal communication systems.

This new technology means that you can receive voice, text, and get paged through one unit. It will probably also be able to receive graphics and video. So maybe in the future we are going to be looking at a video telephone. These already exist but they are not available everywhere, and they are not that great yet. But you may eventually be able to sign and lip read over the phone. This is the direction we are heading. (See Figure 5).

Analog and Digital phones.

Analog is the slightly older technology. What I want you to know is that most of these phones are not hearing aid compatible. That means that they do not have the telecoil built in, so you can’t use them with a hearing aid telephone switch setting. Many analog wireless phones are TTY compatible with acoustic coupling, meaning you can take the handset of the phone and put it on your TTY.
Figure 5

The Wireless Future: Voice, Text, Graphics, Video
M. Bakke and A. Haravon

Audience:

What is the definition of analog?

Matthew Bakke:

Analog is really the opposite of digital. Digital means a signal. A sound is transformed into numbers. Analog means the sound is not transformed into numbers but the sound is rather represented by electrical energy. All of your technology that you have in terms of radios, tape cassettes, record players, they are analog. The good example is the tape cassette versus the CD. The audiotape basically takes a sound, transforms it into electrical energy, and then puts an electromagnetic signal onto the tape. And really the electromagnetic signal is just more or less energy as you move along in time. It is a direct representation of the sound in a different media. Instead of acoustic sound or sound, it is now electrical energy, or in the case of a tape, magnetic energy that changes over time. But it is direct -- almost like drawing a picture of the acoustic energy. Digital, instead of just drawing a picture of it, changes it into numbers and draws a sketch of it in numbers. Instead of being a smooth line, it is dot-dot-dot-dot. It is just a different way of representing the same thing. The advantage of digital is that you can do things to it mathematically, whereas with analog you have to do things electrically. A CD is digital because the sound is represented by numbers. A tape is analog because it is represented by magnetic energy.

Audience:

How can you tell if you have an analog phone or a digital phone?

Anita Haravon:

You can't tell by looking at the phone. You have to ask the dealer.

Digital wireless phones allow for both voice and data (text) transmission. But the problem is, for TTY users, that TTY signals are not compatible. You cannot transmit TTY signals on these digital phones. The digital phones change sound (in this case speech) into bits of data. Speech is encoded into a series of ones and zeros, and then it is transmitted, sent to whoever is receiving it, and then changed back into speech. The problem with that, for TTY users, is that this equipment is designed to be used with speech, not with the TTY beeps. TTY beeps are very different from speech. Now industry and researchers are beginning to work on this problem. Another issue is that digital wireless technology sends out a signal which can cause interference with other electromagnetic devices such as hearing aids, pacemakers, and supermarket checkout scanners. That means that if I have a digital phone and I turn it on, and let's say somebody close to me has a hearing aid,
they may actually pick up interference when I turn my digital phone on. They may hear noise. If I have a hearing aid on and I try to use the phone, I can't because all I am hearing is interference. I am not going to hear any speech.

Many of us are concerned about this problem because it means that this new technology is not accessible to people who use hearing aids. Therefore, hearing aid manufacturers, the digital wireless manufacturers, TTY manufacturers, the FCC, consumer groups, like SHHH, ALDA, and research centers like ours are working to solve this problem.

Some practical advice: If you are thinking about buying a wireless phone, it is very important that you ask the salesperson if the phone is analog or digital. I also want to mention that you can directly connect your TTY to some cell phones by plugging it in, if you have a direct connect TTY and you have a cell phone that has a special jack which is called an RJ-11 jack. It is important to educate yourself. Sales people don't know that most of the cell phones are not compatible with hearing aids and don't work that well with TTYs.

Audience:

Have you done any research with the Hatis system?

Anita Haravon:

The Hatis is another device that can be used to make cell phones hearing aid compatible. It's something that you use with your telecoil switch. It is a solution, but we are pushing to make cell phones hearing aid compatible so that you don't need an extra piece of equipment.

Matthew Bakke:

At this point we would like to do two things. One is answer any questions that you would like to ask about what you have seen or other issues. The other is that we want to hear from consumers because we believe strongly in a research model that is called participatory action research. We want people with hearing loss involved at every stage of the research, from the very formation of the research question, to the design of the research, to the carrying out of the research, to the dissemination of the research results. We have put a lot of effort into working with consumers as much as possible at meetings such as this, at local SHHH and ALDA meetings in New York, wherever we can get in touch with consumers.

So where are we in our RERC now? We will have finished the five year grant this coming May which completes the five year cycle. We will be reapplying for an additional five year grant in January. In that process we receive from the
government certain priorities. These are the things that we study for the next five years, and they give us those. But they are generally pretty wide open questions. What we would like to know is what do you have in your minds in terms of technology? What are you looking forward to in the future in technology? What kinds of access problems are you having now that you think maybe technology would be helpful in? Because we can take that information and we can build that into our project. That is the kind of input that we are hoping to get from you.

Audience:

One problem that I had was trying to communicate internationally on the TTY because the code isn't the same. Is there anything available to help you do that?

Matthew Bakke:

Yes. Back about five years, the problem of TTY compatibility had been addressed. The large part of this work came from Gallaudet University with our colleague, Judy Harkins. The problem is not only international communication but also within the domestic United States where there are really two TTY systems. There is the Baudot TTY system, which is the sort of standard TTY that we have which is slow and doesn't have a lot of features. Then there is the ASCII TTY signal which is more in line with computer language and can be received and sent through your regular computer and a regular modem. So there is that confusion. Then there is the international confusion. Internationally they use different kinds of signals for TTYs. A whole group of people came together to talk about this problem, including consumers, the TTY industry, and researchers. Eventually, they did come up with a new TTY standard. It is called the V.18. Now, this standard is available. You can get a copy of it on the Internet from Gallaudet University. It is a written standard which permits communication between Baudot TTYs, ASCII TTYs and international systems. So the standard is there. The process that we are going through now is getting that standard built into new modems. In other words, industry has to pick it up and put it into their instruments. With instruments which have V.18 built into them, you could communicate internationally.

Audience:

You were talking about this FM hearing aid, and we also talked about digital hearing aids. Well, the problem that I have with mine is the background noise, which you said the FM would improve on that. Another problem is that when the sound gets louder, it gets distorted. So when it gets louder, it is not clear. It sounds like, from what you have said so far, that the FM would do more to cope with those problems than the digital. You didn't say anything about the digital, if that has any effect on those or not.
Matthew Bakke:

Well, digital might be helpful with the second problem you were talking about, with the limiting. When the sound gets very loud, it gets distorted and you can't understand it. You can do this with analog hearing aids as well. But with some of the digital hearing aids, they have nice processing schemes that sort of keep the sound at a level that is comfortable for you. Some of the analog hearing aids also do this very well, but there are individual preferences. Some people have tried analog hearing aids, very good ones, for a long time, then go to the digital ones and they think they are wonderful. They really do. And I have heard comments about how wonderful these hearing aids are. But other people have gone the other way. They have tried them, and they really did not find them any better. So it is a very individual kind of thing and you really need to go through the process of trying hearing aids.

A basic principle that I believe in, although it is strictly my bias, is that you start with the easy solutions and move to the more difficult ones. You start with the cheaper solutions and move to the more expensive one, not the other way around. Sometimes people are getting their first hearing aid, and they walk in, and they want to buy a $4,000 hearing aid. My approach to that would be, why do you want to spend all that money right off? Maybe you will get perfect satisfaction from an $800 hearing aid. So why not start with a simpler and cheaper solution and then move up the spectrum until you find what is good for you?

Thanks very much. We appreciate your attention.

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