FACING DEAFNESS

Edited by
Stephen J. Larew, M.A.
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Douglas Watson, Ph.D.

Proceedings of ALDACON III
The Association for Late-Deafened Adults
November 6-10, 1991
Chicago, Illinois
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PREFACE

This document represents the first publication of the proceedings of ALDAcon, the annual convention of the Association of Late-Deafened Adults. ALDAcon III was held November 6-10, 1991, at the Westin Hotel in Chicago with more than 225 people in attendance. ALDA is still in the embryonic, all-volunteer stage. This conference reflects the remarkable growth that has occurred since 13 people attended the first ALDA social in March 1987. That group of 13 has now grown to more than 1,800 people and continues to grow as our members spread the word and more people become aware of ALDA.

This outpouring of interest and support makes it clear that ALDA has touched a nerve among late-deafened people. Interaction among late-deafened adults and support groups for them were virtually nonexistent before ALDA. A variety of activities and support services for late-deafened adults are being developed through ALDA. Self-help groups, socials, and the use of realtime captioning represent some of the efforts put forth by ALDA members.

The annual ALDA convention has become the organization's flagship. ALDAcon allows ALDA members, family members, friends and professionals the opportunity to meet other ALDAns, share experiences, receive self-help and leadership training and other information related to deafness. Most importantly, ALDAcon offers the opportunity for people to experience stress-free communication and enjoy themselves.

The theme of ALDAcon III was "Facing Deafness", which ALDAns did just by attending and meeting peers can play a vital role in helping people adjust to their hearing loss. Once a person is able to see they are not alone, it is easier to admit to being deaf and to face the reality of deafness. As Gallaudet University president I. King Jordan stated in his keynote presentation, it is important to not let deafness become a negative, and to take a positive approach. It is hoped that the articles published in this document will assist deafened individuals, their families, and friends in making the adjustment to the world of deafness.

Bill Graham
ALDA Executive Director
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Section One:

Keynote Presentations
Let's Face It: We Is Deaf

Bill Graham

Bill Graham is Life Sciences Editor of The World Book Encyclopedia and Executive Director of the Association of Late-Deafened Adults. He also is a Trustee of Gallaudet University and the National Court Reporter Foundation. All in all, he'd rather be biking.

My name is Bill G. and I am a late-deafened adult. Whew! There, I said it: I'm deaf. The hardest part is over. Let's party! No, really--I've always had a hard time saying that word: deaf, deaf, deaf. Eight years ago I wouldn't have touched that word with a forty foot pole. It was just too embarrassing to admit that I couldn't hear. And I'm not a guy who gets embarrassed easily.

For example, I'm a Cubs fan...I admit it...I've been a Cubs fan all my life. I don't apologize for it. And I'm very capable of facing the fact that the Cubs stink! They're overpaid babies! But hey--I'm a fan. Take me for what I am. I have no sense of shame.

There are plenty of things about my life that would embarrass most people, but not me. I didn't keep a checkbook until last year, after I got married. I was 37 years old. Until then, I never knew exactly how much money I had left at any given time. I bounced checks with the phases of the moon--still didn't wise up, I never kept a checkbook. My wife couldn't believe it. She thought I was from Mars. Now she's convinced I'm from Pluto. But not keeping a checkbook didn't embarrass me at all. In fact, I was kind of proud of it. Made me seem like a free spirit with unlimited cash reserves.

There are all kinds of things that maybe I SHOULD be embarrassed about but I never have been. But deafness...deafness...that's another story. When I gradually lost my hearing after high school, I was terribly embarrassed and ashamed. That's not very logical because it wasn't MY fault that it happened. I had nothing to do with it--it just happened. But maybe you understand the feeling.

I was embarrassed--embarrassed that I was so different from everyone else in my life. They all seemed so perfect because they could hear perfectly and I couldn't. I was embarrassed about every communication difficulty that occurred. And I was ashamed--ashamed because I denied my hearing problem for many years and then for many more years I denied the extent of the problem. I was a con artist--I bluffed with everybody, including myself. I ran away from the problem. I just could not face it. It paralyzed me with fear. I didn't want to be different from everyone else. I wanted to fit in and live the life I had been living. Listen to the radio, talk with friends in the dark, laugh at jokes at the right time...you know?
The theme of this year's ALDacon is "Facing Deafness." Oooooooh! Give me a break, Facing deafness?? I paid a lot of money to come to this conference. I want to have a good time! What kind of idiots are on the ALDacon planning committee to pick a theme like that? Why not "Las Vegas Nights" or "Novemberfest"? Facing deafness?? Who the hell wants to do that on a weekend?

Well, I do. I really do. I want to face my deafness... as well as I can. Every day of the year I want to, even on bowling nights. But I don't. I don't even come close. I'm better at bowling than I am at being deaf. More years of practice, maybe. I don't know. A lot of the time, deafness baffles me. I'm a lousy deaf person. Look at how I sign! Maybe some of you think I sign well, but I'm a hack. And this is my most effective way to communicate! It's scary.

But I really do want to face my deafness—today, every day. That doesn't mean I want to be serious and a sourpuss all the time and that I don't want to have a good time. I love to have a good time. I want to party—LOVE to party! I had a great time last night, and I'm going to have a terrific time again tonight, and I'm going to be really wild tomorrow night. I LOVE TO PARTY! And ALDacon is the best place to do it!

But life, alas, is not a 24-hour, neverending party. Eventually, the party hats are put away, the bar closes, people say goodbye... but my deafness remains. It's reality. My reality. I've spent enough of my life pretending to be somebody I'm not. Deafness is ME. And I really DO want to face it. I think we ALL do.

But what does it mean to face our deafness? Do the guidelines for being deaf descend upon us like the Ten Commandments did to Moses? Do all our insecurities suddenly go away, our anxiety, our confusion? Does facing deafness necessarily mean total acceptance of it? Do we ever really accept our deafness? Or are there simply moments of insight that build upon each other until we're comfortable as deaf people.

What does it mean to face our deafness? Well, I don't know about you but I believe that we begin to truly face deafness when we can think about it without being overcome with paralyzing fear. When we aren't afraid to think about our deafness. And eventually, when we aren't afraid to talk about it.

I recently read an article I really relate to in Disability Rag, a periodical by and for people with disabilities. The article is by a quadriplegic woman named Cherry Marie Wade. She writes about the importance of bringing the realities of her disability out into the open— the sense of shame, the lack of privacy, and other realities that make her different from everybody else. This is from the article: "If we are ever to be REALLY at home in the world and in ourselves, then we must say these things out loud. And we must say them with REAL LANGUAGE. So they are understood as the everyday necessity and struggle they are."

I agree with her. We must express our thoughts and feelings about deafness. We must admit the fear and embarrassment we experience attempting simple dialogue with cashiers. We must admit that there are days when we feel that there is absolutely no place in the world for us to fit in. When all the people we meet are nothing more than incomprehensible mouths looking perfectly comfortable in their easy verbal exchanges. I still have many days like that. And they aren't pleasant. But that's how it is.

On the other hand, we must also admit that for many of us facing our deafness moves us just a bit closer into the circle of humanity. A little closer to understanding what happens to people when challenged with what appears to be insurmountable obstacles. We understand
despair and we understand the unflagging strength of the human spirit. We must talk about every aspect of deafness - the tragic, the mundane, and the inspirational.

I did not think or talk about my deafness for many years. I didn't even THINK about THINKING about my deafness. And, ironically, as a result, my deafness dominated me. I was a prisoner of my deafness. I spent all my time and energy trying to avoid the reality of it. It was my demon—the unmentioned tragedy in my family. The elephant in the living room that everyone saw but no one acknowledged. I guess we thought that maybe if we didn't mention the "d" word it would go away.

Well, it didn't go away. It didn't go away. And eventually it just hurt too much not to face it. My self-respect was in the gutter. I was a fraud. I HAD to face it. But it seemed that nobody would face it with me. My parents told me: "Don't make a mountain out of a molehill. " If I was with friends and could not understand them, they'd say: "Oh, forget it--it's not important." Or maybe they would summarize a 15-minute conversation in 10 words or less. Strangers would tell me: "You lipread VERY WELL!" I lipread very well? I mean, c'mmmmmnnn! All these people were well-meaning, they were all trying to be positive and nice—but they were all in denial. They didn't know what to do with me or what to say to me. I was the only deaf person in their lives.

So what was I supposed to do with the things I was feeling—the backwash of deafness: the isolation, the frustration, the anxiety, the confusion, the anger, the embarrassment, the shame? These were all very real to me. And they needed to be talked through and understood or they would always, always haunt me because I didn't believe in myself enough to believe that I could be so different and still be mentally and emotionally well.

Finally I was fortunate enough to meet you—other late-deafened adults. For the first time I entered a world where it was okay to be a man in his thirties who couldn't negotiate a drive-through bank teller. I found a place where I could think about and say exactly how my day went without someone telling me to either join the Deaf Community or that I should be grateful I could speak so well.

No, I told you that I felt different, that I felt shame and loneliness. I told you that when I walked down the street and saw someone coming toward me that I'd cross the street just to avoid the possibility of communication. And you told me you felt and did the SAME THINGS. And that's how we face our deafness. We do it together. And through this process, we free ourselves from some of the demons of deafness.

You help me more than you realize. Because on many days, I'm just tacking into the wind. I can be a real dope about coping with my deafness. I still go up to strangers—seems like every day—and try to pawn myself off as a hearing person. Invariably, this gets me into ALL KINDS of trouble. And I end up asking myself: Is what I just did what I REALLY wanted to do?

We should all ask these questions. Next time you find yourself pretending—again—to understand your bearded brother-in-law ask yourself "Is this what I really want to do?" Next time you get the wrong order at a restaurant but eat it anyway because you don't want to deal with the waiter, ask yourself: "Is this what I really want to do? No Next time you see an old friend from your hearing days in a store or on the street and you sneak away, ask yourself "Is this what I really want to do?" Think about it. Talk about it. Maybe eventually we can change what we do. This is facing deafness.

Now we'll spend the next couple of days meeting each other, and going to some terrific workshops and special events. Say what you feel, do what you like, party your brains
out. But know that by being here and facing your deafness, you help me face mine. I'm glad you came. Thanks.
I. King Jordan

I. King Jordan, Ph.D., was deafened at age 21 as the result of a motorcycle accident. After recuperating from his injuries, he began understanding his deafness and shortly afterwards entered Gallaudet College (now University). He became President of Gallaudet after the Deaf President Now movement in March of 1988. Dr. Jordan was keynote speaker at ALDAcon II and agreed to come back for an encore performance at ALDAcon III.

Good evening, everyone. Before I begin to talk with you - not speak but talk - I need to make a brief presentation, too.

One of the members of the Gallaudet University Board of Trustees is with us tonight. That individual and I, about three weeks ago, made an agreement; some people would call it a bet, but I don't bet. It had to do with a football game. The Washington Redskins played against the Chicago Cubs. Is that the name of the team? This year they are called the Cubs, right? We bet that whichever team won, the loser would wear the other team's colors. So when Bill Graham and I run together tomorrow morning (gives Bill a Washington Redskins t-shirt), Bill will be wearing this shirt.

Mr. Graham: I told King when that fluke of nature happened that there is always the play-offs. Thank you very much. I will see you tomorrow morning.

Dr. Jordan: He is a good sport. A Chicago fan this year has to be a good sport. The title of my talk is "Deaf Today, Deaf Tomorrow". I intend to speak to people who became deaf and talk about what it's like to be deaf and what it's like to stay deaf. Now, I know many, many people who were born deaf, who grew up deaf: and it's interesting to me that the mix of people at this ALDAcon is fantastic. Before, only people who became deaf later in life joined ALDA, now many different kinds of deaf people belong. I think that is reflective of a very positive trend and I congratulate ALDA on that. But, nonetheless, I will talk about what it's like to become deaf. I am not a good model for this because although I became deaf at age 21, I didn't admit I was deaf until 25, 26, or 27 years old. Really, it's hard for me to believe today that it took that long, but, believe me, it did.

I became deaf in 1965. When I became deaf, everyone told me, "Don't worry, you will get your hearing back soon." Doctors told me, "It's only temporary." My family told me, "It's only temporary." My friends told me, "You talk fine. Soon your hearing will come back." It took me a long, long time to realize that physically I became deaf overnight.
Emotionally and psychologically, I became deaf much later. Part of the reason why that happened to me is that there was no group like ALDA. There was nothing like that. This group here is very, very important! You have people who share the same experience, people who can sit down and talk with you and tell you what their life is like and that your life will basically stay the same. Maybe you won't hear, but that's all.

I never had anything like that. There was no ALDA, there was no organization of any kind. There were individuals and we didn’t talk to each other. In fact, if I knew another deaf individual, I intentionally avoided him because he was deaf, not me. I thought that maybe if I associated with that person, I would catch his deafness. I didn’t need to catch his deafness, so I intentionally avoided associating with people who were deaf. I never, ever used the word deaf. Never!! I apologized for not being able to understand. I would say, "I am sorry. I can’t hear." Can’t is an important word. When I talked with my family, when I talked with doctors, when I talked with my friends, the word can’t was always the most frequently used word in my vocabulary. To start and end by talking about what you can’t do is silly.

Once I finally recognized that I was deaf, I said, "I am deaf. So what?" Now, I know I am deaf, put that aside. Let’s talk about what I can or what I hope to be able to do later on, but don’t be concerned about the can’t because once you know what you can’t do, you move on to focus on the things you can do. The most interesting thing to me, on reflecting on my personal experience with deafness, is that I went through Gallaudet University without really admitting that I was deaf. While I was at Gallaudet I learned to sign well enough to get an education but not well enough to really become part of Gallaudet. I was not a very social person at Gallaudet.

If you look at the yearbook and ask people who graduated from Gallaudet the same time I did, many don’t really know me because I was a commuter student. I came, studied, went home, studied, came, studied, went home, studied. In graduate school I did the same thing. "It’s a ridiculous way to get an education, really ridiculous!" Education is so much more than classes and books. There are so many more learning experiences outside the classroom, opportunities for leadership experiences. I missed them all because I didn’t acknowledge that I was a deaf person. It almost makes me feel like a born again Christian or something. I want to tell you: Don’t do that, don’t do that.

If you are deaf today, then you will be deaf tomorrow. You will be deaf next week, next month, next year. Take that, put it aside, and start working on the important things in your life. Deafness is not important. It’s not. It’s a very trivial thing. I wasn’t a very good signer at Gallaudet. I am not known as a very good signer now, but I am better than I used to be, and I learned a lot, I really learned a lot. I really benefited from some wonderful relationships with other students and professors.

Some of my professors are still around – not teaching any more now because they are retired; but I still see them from time to time. They are some very, very deaf people with whom now I can sit and talk. They knew I didn’t accept my deafness, but they were used to that. They had met other people who did the same thing, so they just ignored it. They just taught me chemistry or math or business, and they did a fine job teaching that.

When I left Gallaudet and went to graduate school and so forth, I still focused on the can’t. I focused on the problems, and I have to admit there were problems. When you can’t hear, life is not as easy as when you can hear especially if you grew up hearing and then all of a sudden you became deaf. You are used to talking to people, you are used to listening to people you are used to social interactions that depend on speech and hearing and suddenly
you can't do those things in the same familiar way. It is frustrating, and you tend to focus on that frustration, but don't do that, no.

Remember, some of you were here last year and I told you my story about my experience on the "El." When I was coming into Chicago, I thought I would take the "El." I didn't know where to get off but it was above ground and it was easy for me to see the loop area. Then we went underground. I didn't know where I was so I went up to a conductor and asked him where should I get off. I couldn't understand him so I repeated. Again, I still couldn't understand him. I knew I would never understand him, so I asked him to point to the map, you know, a simple request, I asked him to point, to show me where the "El" stopped. He was mad. He really got upset because I embarrassed him. It embarrassed me, too. Now we made a scene. People on the "El" were all watching us.

He was embarrassed. It was a clumsy kind of thing. Those kinds of experiences happen and they will happen again. It might happen to me tomorrow. It might happen to you tomorrow. It might happen next week. It is a part of life. It is not a big deal. It is not going to damage your psyche. Maybe it would damage your ego a little bit, but that's part of the hazard of deafness. We simply have to learn to recognize that these things will happen.

People out there don't understand deafness. Hearing people still don't understand deafness. When you talk with a hearing person about deafness, the only thing they can do is try to imagine what their life would be like if they couldn't hear, and all they can do is think of the negatives that would exist in their life because they can't hear. Hearing people can't understand deafness. We must educate them. We must help them recognize that deafness is not a big deal, it's not. It's just one difference in a society that is made rich because it is full of differences. We can offer many, many interesting ideas, interesting experiences, and different perspectives to that society. If hearing people are really smart, they will benefit from that. We can help them learn something new. It is interesting that hearing people are often afraid of deaf people. Really, I use that word, afraid. I have experiences from time to time when I can see that people who are otherwise comfortable suddenly become very nervous. I was at a hotel and there were two lines at the desk. A woman was working there helping someone else and she was talking to the person. She was easy to lipread. You know, how some people are easy to lipread? I could understand everything she said. I sat and watched that whole conversation.

When she finished, she came to help me. She asked my name and then she was looking for a card and she talked while she was looking down. So I said, "You can't talk downward because I am deaf. I have to read your lips." After that I couldn't understand one word she said because she tried to help me understand. "Sorry." I don't know what she did to her face but she changed. She was a different person, and I couldn't lipread her. If she talked to somebody else, fine, but, once she knew I was a deaf person, she was afraid. She was really afraid to try to communicate, to associate with me as a deaf person. The only thing we can do is keep talking to people, keep insisting that people associate with deaf people, and, after a while, people will become more used to and comfortable with deaf people, and we will get along well with that.

When people become deaf, often the first thing that suffers is relationships with families and friends. Of course, communication is the problem—communication between husband and wife, between father and son. About 80% of the communication you have with your wife, husband, whomever, is not very important, just chitchat. True, just talk. And that kind of conversation is healthy. It keeps people on the same wave length, but if you have
communication problems, you stop doing that. The only time you talk is when you have something important to say, and, often, that important thing may be negative, so a lot of the positive, funny, light conversation disappears. You can't do that. You have to find a way to continue day-to-day chitchat, the opportunity to leisurely, freely, and comfortably talk with each other all the time. That's the first thing that disappears.

I experienced that a lot when I first became deaf. I learned later that you can't let it happen. You have to insist, and sometimes it's hard. It's hard for the deaf person, it's hard for the hearing person. You just have to work at it. You have to get it to work. One of the things that bothered me when I was preparing my remarks here is the knowledge I have that it's easy for me to talk about deafness in a positive way because for me, personally, there is no question that deafness is an advantage. I mean, I wouldn't have my job if I wasn't a deaf person. I would never have appeared on "60 Minutes" if I wasn't a deaf person. I would never have done that if I wasn't a deaf person. I know that, and I know for most of you that's not true. I know if you are lawyers or doctors or clerks or wives or whatever, deafness is not an advantage, but don't let it become a disadvantage.

That's easy for me to say. All I can say is that in my private life, my family life with my wife and my children, with my sisters, deafness doesn't help me there, but it's not a disadvantage either. I won't let it become a disadvantage. If you insist it can, deafness will help you a great deal. The idea that to become deaf is painful is true. A lot of people use psychological models that follow the grieving process of a significant loss and probably some of that is very true. If you want to talk about becoming deaf, then 1991 is a pretty good year to become deaf. If you have to become deaf, now is a good time to do it. There are two main reasons why that is true.

**Attitudes**
The first is attitudes. People now are more receptive, more positive, more open, more curious about deafness than ever before. Now, for example, when you travel before if you traveled or went to the movies or anywhere and and used sign language, people would look at you and give you curious, maybe dirty looks, but now you go out, sign or travel, people come up and they try to introduce themselves. Some people who can only fingerspell still come up and sign to you. That's wonderful! Be patient, because that's a good sign that hearing people want to know more about deafness, and they want to give deaf people every opportunity to participate in society. I think that is a tremendous thing.

**Technology**
The second reason that 1991 is a good time to become deaf is technology. Wow. We're here with AT&T and we have telephones and captions. When I was a student at Gallaudet in 1968, we had what they called a telewriter. Anyone here remember the telewriter? It was an awkward thing. It was a machine that had a mechanical arm and you put a pen in and wrote with that arm. The phone then hooked up to another machine and it wrote.

At Gallaudet we had two of those; and I can remember one day sitting down and communicating with a woman named Barbara Kannapel writing back and forth. It took us about a half an hour to say two paragraphs to each other. It would have been much easier for us to use a tin can and a wire to communicate, but that was the start. It was no TDD. Now everybody has TDDs. I have my compact TDD in my room. Everyone uses TDD's. I have a car TDD. I have been stuck or late, and I use the TDD to call someone with an important message.

**Computers**
At Gallaudet I almost never use the telephone. I use computer electronic mail and can contact people all over the world. When I was in Japan during the summer, it was easy for
me to contact my office via electronic mail. There was a 12-hour time difference, so hearing people had a hard time calling because it was tough to find a time, maybe 11:00 o'clock at night, 11:00 o'clock in the morning, to get a phone connection. Just use electronic mail. You can send it any time and people read it when it's convenient and deafness disappears. People on electronic mail don't know if the people with whom they are communicating are deaf or hearing. It's all the same using a computer.

Hearing Aids and Cochlear implants
The hearing aid technology has advanced as has the technology related to cochlear implants. For people who benefit from those devices, there are now many more opportunities for their use.

Fax
Facsimile technology has changed the American deaf community. I know people who have fax machine in their cars. I know a deaf man in Scotland and I communicate with him regularly by fax from Scotland to the United States. Before it took eight weeks for a letter, now in eight seconds you have a fax in your hand.

You remember if you saw me on "60 Minutes" that the woman asked me, "If I could give you a pill to make you a hearing person, would you take it?" She really offended me by asking me that question because it's not a serious question. There is not a possibility of it happening and that is exactly the kind of thing that has caused so much pain and difficulty with people trying to adjust to deafness. It lets people delay acceptance. It lets people hold onto the notion that, "Well, today I am deaf, but maybe tomorrow that pill will exist." Maybe. It's not a smart thing to do. That's why I called my speech "Deaf Today, Deaf Tomorrow" because if you are deaf today, you will be deaf tomorrow too. You really don't have a choice. If you are deaf, you are deaf.

One of the things I hear over and over again is that people are afraid they will change. You won't change. You are the same person inside that you always have been. Your ears don't work but the rest of you is the same. Recognize that and stay the same. Be yourself. Be like you used to be and you will be fine. Value yourself. Don't let anyone tell you that because you are deaf, you are less of a person. You are not. Don't let anyone tell you that deafness moves you down a notch. It doesn't. Deaf people are every bit as good as hearing people and make sure that you keep the same high level of self-esteem that you had when you could hear. Be yourself, value yourself, and you will succeed. Thank you very much.

I was informed that I can answer questions. If anyone has questions, I would be happy to respond. Questions?

Question: Does your family sign?

Answer: My immediate family consists of my wife and two children. My wife interprets for me. My son, signs okay. My daughter is a good signer. My mother and father are both passed away. My sister signs well. Cousins, nephews, nieces, I don't see them often enough. My closest sibling is my sister, and she signs fairly well, well enough that we can talk to each other. I started to say my son grew up when I wasn't deaf. My son grew up when my ears didn't function and I didn't sign at home. I talked to my wife and I pretended. That's something else you can't or shouldn't do. I pretended I understood a lot more than I did. I caught the deaf smile. People talk to you. I don't know what they are talking about. So now I try very hard not to do that. If I don't understand, I ask, "Please repeat. Thank you."
Question: What was it that made you become deaf instead of just a person who didn't hear?

Answer: That's really a good question. I have thought a lot about that. I don't know the date when it happened. I went through undergraduate school and graduate school. I went back to Gallaudet. When I started to teach at Gallaudet, right away it was clear to me that I couldn't sign well enough to function in the classroom. I met some other people there who I had a lot of respect for. I don't know exactly how or when it happened, but all of a sudden I realized, "This is for keeps. This is something that will be permanent." I resent the fact that the doctors who cared for me in the military mislead me. I don't know if it was intentional or not, but they definitely told me that my hearing loss was temporary. They told me that several different times. One time they said, "In six months you will be able to hear again." Then after six months, they said, "Well, unusual. In about a year you will be able to hear again." Then, after a year, they said, "Well, you really, really are unusual but in a couple of more years you will be able to hear again." Again, again and again they did that. You know, it's my own fault. I accepted it. I really should have been smart enough to know: Fool me one time, okay, but fool me two, three, four times, then it's my fault not their fault, I guess. I wish I had a more specific answer.

Question: Could you tell us something about the college and the changes at the college?

Answer: Let's see. Changes in the college?

When the students took over the University, it started as a protest. I went to dinner last night at a club in Washington, D.C. where they give scholarship money to the University, and the President of that club told me in a conversation, "In 1988 I didn't know anything about Gallaudet, I didn't know anything about deafness, but I sure had an opinion". You know, I laughed. A lot of people did. That protest changed very quickly from a protest to a revolution and an important social change. Part of the social change was empowerment of the students and of deaf people in general. Well, that's what I am leading to, empowerment. The students are still empowered. They are a very, very strong group of students. They make regular demands. This week it's parking. Next week, I don't know, but there are tensions at Gallaudet and that's very, very healthy. There is always tension between the faculty and the students, between the administration and the students, because they are empowered. And people have asked me, "Well, wouldn't it be easier if they were apathetic". The answer is sure, it would be easier to administer, but given the choice, I will take the empowered students any time and deal with the confrontations.

That's the biggest change. The students, the faculty, the staff all are empowered and all have a sense of ownership of the University. They really feel they own the University. I think that's outstanding.

Questions: Tell us the story about the ghost in your house. It's a classic, really. It's great.

Answer: This is a true story from when I moved into the house in April, 1988. There is a ghost in that house, there is at least one ghost in that house. We have a very sophisticated alarm system in the house and it has eight different zones. If you open a back door, it's zone four. If you open a front door, that's zone five. If you open the basement, that's zone two. Well, one night we went to bed. I was asleep, and my wife was awakened by the sound of the shutters moving. She looked out the window, and there was no wind or anything. The trees were still, no wind, but she heard that noise. So she woke me up. She said, "I heard a noise outside and there is no wind." I said "Shut up. Go to sleep." So I went to sleep. Right after I went to sleep, the alarm system went off, and the whole house—bang, bang, bang. Security came because the alarm system is hooked up to the
security outfit. They came into the house and we looked at the alarm box. It said zone seven. So we got out the book, "Let's see, where is zone seven in that house?" Remember, we had just moved into the house. "That's the second floor bedroom window." The window where my wife had heard the noise. Security went up and checked the window, very carefully, and checked to make sure it was closed. They said there was nothing wrong. "Really, it should not have gone off. There must be something wrong with the system. It just happened. So don't be concerned. Go ahead and sleep." So we re-set the alarm and went to sleep. Well, the second I went to sleep, bang, bang, again. Sure enough, zone seven again. Security came again and checked and checked and checked. Everything was fine, no problem. I was fed up. I told my wife, "Don't re-set the alarm. Leave it off, and we will go to sleep." We did, we went to sleep and it was fine.

We eventually discovered what was happening. It was the ghost of Edward Miner Gallaudet. He was checking with the alarm, if it woke me up, to see if I was deaf. When he was satisfied there was a deaf president, he stopped bothering us. Since you are asking, we have had about five or six additional encounters with ghosts. Just about two or three weeks ago my wife woke me up because she heard the door open and close. She said absolutely that she had heard the door open and close, and it had not opened and closed quietly. Then she heard someone walking up the stairs. You know, in an old house, the stairs have very specific sounds, each step. She heard the person walking up the stairs, and she woke me up. She said, "Someone is walking up the stairs." I jumped out of bed, turned on the lights. Nobody in the house. My wife was not satisfied. We called security. Security came, checked the closets, checked under the stairs, checked the whole house. Nobody there. The alarm was set, so no one could have come into the house. We are convinced, really, that Edward Miner Gallaudet or maybe Sophia, Sophia Fowler Gallaudet is there and keeping us company and protecting us. They are friendly ghosts! That's fine.

**Question:** Several years ago I asked you if you would think about the possibility of setting up a center at Gallaudet for people who become deaf similar to the Helen Keller Center for people who become deaf-blind. What has happened? Is anything progressing on that?

**Answer:** We have a growing College of Continuing Education and one area in that College of Continuing Education is called special populations. We haven't really begun to address this in the way we should, but recently we had a meeting and we discussed the growing incidence of people becoming deaf later and how no one deals with that. So, perhaps we will look at it when we open up our new conference center for training and development. The center is funded mostly with Kellogg money. It will be like a hotel with conference facilities on campus – maybe we can do something like that. I have to tell you that I don't have a program, but what you said is a very good idea.

**Question:** As President of Gallaudet, regarding the late-deafened adults, how do you deal with the late-deafened adults and the people who are born deaf and the culture difference?

**Answer:** That's a very difficult question to answer, because when I became president I tried very hard to be very inclusive, not exclusive. I want to define Gallaudet's role as serving and educating deaf people, deaf and hard-of-hearing people. The definition includes everyone who is deaf and hard of hearing.

I don't think Gallaudet should only be for the Deaf culture. I think Gallaudet should be for people who are deaf. So in many ways programs will address differences, not just people from Deaf culture. I didn't grow up in the Deaf culture and there are many things I don't know about growing up a deaf person, but I can learn and I do learn. I sit down with people who did grow up deaf and listen to what their experiences were. I just try to be as
inclusive as possible and not think of Gallaudet as serving one kind of deaf people but all deaf people.

**Question:** In your opening remarks you said, I think, "I am not a very good role model." As you speak, I don't know anyone better.

**Answer:** Well, thank you. Thank you very much, I want to stop there.

**Question:** I want to ask you a question, a general question about supporting individuals on their communication—sign, fingerspelling, interpreting, or written. Now, at Gallaudet University suppose a teacher happens not to use sign language and a deaf student would prefer to ask a teacher to use an interpreter. Would Gallaudet support that?

**Answer:** Gallaudet does now. It used to be that Gallaudet would hire new teachers, give them eight weeks of training, put them in the classroom and they signed however they signed. Now Gallaudet is much better and we give teachers more training. Still if they are not comfortable signing for themselves, we permit them to use interpreters until they become comfortable. Gallaudet, related to communication on campus, really is making fantastic progress. Now we use the SCPI. SCPI means *Sign Communication Proficiency Interview*. We interview every employee at Gallaudet from people who mop the floors, to people who are psychologists, to people who teach, to people who mow the grass, to people who drive the buses. Everyone gets interviewed and evaluated. Employees are expected to meet the level of sign communication that's required for the job. For example, a psychologist would have to be a skilled signer to be a successful psychologist, but a grounds person, who rakes leaves, doesn't have to sign fluently. He or she needs basic sign. We will require people to meet their expected level of sign skills and if they can't, we use interpreters, yes. Thank you.

**Mr. Graham:** King was our keynote speaker last year at ALDAcon II. Not many conferences have the same keynote speaker two years in a row, but I think you can understand why we asked King to come back. He is a remarkable man and a remarkable role model, as Harold pointed out, to late-deafened adults and other deaf adults. We are truly very, very honored and grateful that he is such an enthusiastic and committed supporter of ALDA. As an indication of how much we value his commitment, the ALDA Board of Directors recently unanimously voted to name an annual award after King Jordan beginning next year in 1992. The award will be called the *I. King Jordan Award for Distinguished Achievement*. It will be presented each year to the late-deafened person - any late-deafened person - for eminent accomplishments in a career of long-term endeavor. We will publicly ask for nominations from around the world. I am sure in years to come this presentation of the *I. King Jordan award* will become one of the highlights of ALDAcons in the future. We think that it's only fitting that the first person to receive the award should be King Jordan himself.

We did not put his name on the award this year, because we thought that might be too embarrassing if we put your name on the award this year. It would be like making your own award. So, for this year only the award is called the ALDA Award for Distinguished Achievement and from this date forward the award will be called the *I. King Jordan Award* for Distinguished Achievement. Thank you for being here again.

**Dr. Jordan:** Thank you very much.
An Introduction to the History of Deaf America

Jack R. Gannon

Jack R. Gannon, LL.D., is a Special Assistant to the President at Gallaudet University in Washington, D.C. Dr. Gannon is the author of Deaf Heritage and The Week the World Heard Gallaudet.

I realize that the world of deafness is new to many of you. I became deaf when I was eight years old so I guess I can say I have been around for awhile. I would like to use this opportunity to acquaint you with some interesting historical facts about our deaf world. Personally, I have found it a fascinating and interesting world.

Did You Know That . . .?

In the Texas panhandle there is a county named Deaf Smith. It honors Erastus "Deaf" Smith. (He was actually hard of hearing.) He gained fame as a scout and spy in General Sam Houston's army that fought for Texas' independence from Mexico. Smith's profile also appeared on the Republic of Texas' five-dollar bill.

Nellie Willhite is believed to be the first deaf person in this country to learn to fly. She may have been the first in the world. She got her pilot's license about a year after Charles Lindberg flew across the Atlantic Ocean in 1927. She was a charter member of an organization of women pilots of which Amelia Earhart was president and one of the founding members. Willhite died in the fall of 1991.

Did you know that the classified ads you read in the newspaper were invented by a deaf printer named William Beadell?

Last year Gary Malkowski, a Gallaudet alum, was elected to the Ontario Canada Parliament.

A deaf man, Charles Moskowitz, taught his little dog to respond to commands in fingerspelling. If any of you are finding it hard to learn to read fingerspelling and find this hard to believe, let me tell you that Robert Ripley of Ripley's Believe it or Not would not believe it either!!

Are you aware that today there are at least 16 states that recognize American Sign Language as a legitimate language?
I am sure you have heard that the football huddle originated at Gallaudet University. Gallaudet was one of the first colleges in the Washington, D.C. area to field a football team and Paul Hubbard, the Gallaudet quarterback, is credited with starting the huddle to prevent opposing teams from stealing his signals. The football field at the Kansas School for the Deaf in Olathe is named for Hubbard.

And, while on the subject of football, did you know that the first football coach at Purdue University was a deaf man named Albert Berg?

In my research I found that during the Civil War there were at least four deaf soldiers. I think there were probably more.

Did you know that Gallaudet University is possibly the only college or university in the United States that has statues honoring both father and son? We also have a residence hall and an attractive memorial honoring Laurent Clerc, the first deaf teacher of deaf students in America.

LeRoy Colombo was a deaf lifeguard and a record-breaking swimmer. He saved over 900 lives! His feat is listed in the Guinness Book of World Records. He was a graduate of the Texas School for the Deaf.

Do you know what Alexander Graham Bell, Thomas Hopkins Gallaudet, and Samuel F. B. Morse had in common? They all had deaf wives. Bell’s and Gallaudet’s mothers were also deaf.

Dr. Andrew Foster, the first Black deaf person to graduate from Gallaudet, established at least 20 schools for deaf children in west Africa. He was killed in an airplane crash on his way home to America in December 1987. He is remembered as the "Father of Education of the Deaf in West Africa."

Did you realize that over 100 school gymnasiums, auditoriums, and athletic field, libraries, residence halls, school buildings, and campus streets in this country are named for deaf persons?

Prior to the "Deaf President Now" revolution at Gallaudet University there were only three deaf administrators of schools for deaf children in the United States. Today there are 17 deaf or hard-of-hearing educational administrators.

Did you know that the fastest woman on earth is a deaf woman named Kitty O’Neill? She was deafened at the age of five months. She set a land speed record of 392 mph. in 1977 in a rocket-powered car.

Are you aware that baseball umpires began using the hand count for the benefit of a deaf professional baseball player named William "Dummy" Hoy? Hoy played for the Cincinnati Reds. (A committee is trying to get Hoy recognized by the Baseball Hall of Fame). He will be inducted into the Ohio (state) Baseball Hall of Fame this year.

Cadwallader Washburn was a world-famous dry-point etcher. He was deafened at the age of five years. His work hangs in museums in the United States, France, England, and the Netherlands. The Industrial Arts Building at Gallaudet University is named for him.

In Tennessee there is a deaf deputy sheriff!
I have a list of about 200 deaf authors, 75 deaf persons with pilot's licenses, 150 who have earned or are working on their doctorates, and approximately 100 who have received honorary degrees.

I am sure some of you know Kenny Walker who plays for the Denver Broncos professional football team. He played for the University of Nebraska. During his last home game, when the graduating seniors were recognized, a stadium full of fans gave Kenny the "deaf applause!"

These are just some examples of information about deaf history. Much of this information can be found in Deaf Heritage. Much more remains to be found and documented.

The Deaf President Now Protest

I am sure most of you have heard about the "Deaf President Now" protest that occurred at Gallaudet in March 1988. Let me briefly summarize what happened that week. Of the final three candidates for the position of president of the University, two were qualified deaf persons. The third was a hearing person who had no sign language skills and little or no experience working with deaf persons. The board hired the third person. Stunned and shocked, the students and their supporters locked the campus gates and closed down the University. The students issued four demands:

1) That the new president resign and the board select a deaf president;
2) That the chair of the board resign;
3) That the board be increased to 51% deaf representation; and
4) That there be no reprisals against the protesters.

What followed proved to be a very exciting week. It was an event whose time had finally come. And, as the whole world watched it became a protest felt by deaf people throughout the world.

Do you know what surprised most people about that week? People were not surprised that the students closed the University for one week. People were not surprised by the student's four demands or that they communicated those demands in sign language. What surprised people the most was the fact that in Gallaudet's 124-year history the University had never had a deaf president!

The "Deaf President Now" movement gave us many things. It gave us increased visibility. It taught the world much about deafness and deaf people and their leadership capabilities. That week our students also taught the world that it is still possible to achieve change in a positive, assertive, and non-violent way.

And, most important of all, that week gave us a deaf president! Tonight you will get to meet that deaf president. He is your banquet speaker.

Of course some humorous incidents also occurred during the "Deaf President Now" movement. One such incident involved a young teacher. During the week almost all of the people wore orange badges proclaiming, "Deaf President Now!" All, that is, except for a young male teacher at the Model Secondary School for the Deaf on the campus, he wore a handwritten note that read: "Not Yet." His note caused a lot of raised eyebrows and many individuals thought he had a lot of nerve until one person took the time to ask him what his
note meant. "Well, you see," he explained, "my wife is expecting a baby. She is due any
time now, and I get tired of answering the same question over and over again!"

**Daniel Chester French**

I would like to close with the following story.

Do you know what former U.S. Presidents James A. Garfield and Abraham Lincoln and
the Minuteman in Concord, Massachusetts and John Harvard in Massachusetts and
Gallaudet University have in common? A man named Daniel Chester French.

Who was Daniel Chester French? He was a hearing man who became a great American
sculptor. Gallaudet University likes to believe we "discovered" him. Here is the story.

James Garfield was a congressman from Ohio. He was a great friend of deaf people and a
strong supporter of Gallaudet college. When he became our 20th president he continued his
interest in our young college. His last public address was given at Gallaudet six months
before he was assassinated. When he died the students, faculty, staff, and alumni were
very grieved. They raised money to establish a memorial to him. They commissioned a
young sculptor named Daniel Chester French to create the Garfield bust that still sits in our
Hall of Fame collection in Chapel Hall.

Some years later the National Association of the Deaf commissioned French to do a
memorial of the Rev. Thomas Hopkins Gallaudet, one of the founders of education of
deaf students in America. This famous memorial depicts Gallaudet teaching his first
student, Alice Cogswell, the letter 'A' of the manual alphabet.

French's fame spread. He did many other sculptures including the Minuteman in Concord
and the one of John Harvard, the clergyman and philanthropist, in Harvard Yard in
Cambridge. About twenty years after the Gallaudet Memorial, French did the Lincoln
Memorial in Washington, D.C. Deaf people are especially attached to this memorial for
two reasons: 1) It honors Lincoln who signed our University charter; 2) It appears to show
a weak likeness of the letters 'A' and 'L' in Lincoln's hands. We like to think that French
did that on purpose. We like to think that while sculpting Lincoln he remembered Gallaudet
and deaf people.

**Our Heritage**

Why is our heritage so important to us? I like to think because it identifies our struggles
and our successes. It gives us a sense of pride and encourages us onward. It conveys a
message to our young deaf people that deafness, while a barrier, need not be a blockade
and for the ambitious the sky is the limit. Knowing our history challenges young people to
do better, to go further, to aim higher. I think when we learn about ourselves and our
heritage we become better persons, more whole and more complete.
Yesterday: Chicago, Today: North America, Tomorrow: The World

Holly Elliott

Holly Elliott is a retired marriage, family and child counselor who served on the clinical staff at UCSF Center on Deafness from 1970 to 1980 and was an instructor at San Francisco State University from 1980 to 1989, where she was coordinator of the Independent Living Skills Language Laboratory and part-time instructor in rehabilitation counseling and special education. She is currently co-principal investigator of the Adult Onset Hearing Loss Project at Langley Porter Psychiatric Institute, University of California, San Francisco. Mrs. Elliott became severely hearing-impaired at age 19 and, after a progressive loss, had a cochlear implant in 1987.

Roy Miller, in his workshop this week, asked us to “think globally.” I can support his directive with my own experience during the past few months. Our research on adaptation to adult onset hearing loss has taken us all over the United States, interviewing people who have been nominated by their peers as “successful copers” with adult onset hearing loss. It has also taken us to two foreign countries to share some preliminary results. Research results were presented at the XI Congress of the World Federation of the Deaf in Tokyo, July, 1991 and at the French-American Foundation’s Colloquium on “Deaf in Society: Education and Access” in Paris in October, 1991. Each conference had a different message for ALDA.

Attending the conference in Tokyo were seven hundred participants from fifty countries, and more than one thousand participants from Japan. Two papers on “Late Deaf” were presented at the Scientific Commission on Psychology and Psychiatry. Laurel Glass, AOHL Project Director, and I shared our presentation, and Liisa Pollanen of Finland discussed her work with "DAs" (deafened adults).

Liisa, who was deafened by bilateral acoustic neuromas fifteen years ago, was employed by the Finnish Federation of Hard of Hearing to seek out deafened adults. An article in the newspaper resulted in 350 responses. Two hundred DAs wanted to be added to the mailing list and 150 hard of hearing people wanted more information. A quarterly newsletter is now distributed to 800 people. The Federation set up rehabilitation courses and began making referrals for communication therapy and counseling. Three ten-day courses are currently offered, covering psychological aspects, rehabilitation, technical aids, lipreading,
sign supported speech, and use of an interpreter. Sweden offers seven weeks of training in sign language that augments speech. Norwegians can study sign language at a folk high school for a full term. Other Nordic countries also have good rehabilitation systems. There is wide use of a note-taking system called "interpreting in typing" that utilizes computers and overhead projectors. Future Federation plans include:

- rehabilitating relatives
- improving the work conditions for interpreters
- extending communication training
- improving "interpreting in typing"

How does one communicate with deaf people from 70 foreign countries? I certainly could not speak or lipread Finnish, and Liisa could not understand my signed English; our sign languages were completely different. So we both wrote in English and then shared copies of our written presentations. Liisa dealt with this like a true born-again ALDAN. I quote from her paper:

"I attempt to speak English now. I have learnt it at school which I finished about twenty years ago. So, if you don't understand my pronunciation, please act as a deafened person and look at the written copy of my manuscript on the overhead projector! Or if you think now "Oh, how wonderful to hear a deaf person speak a foreign language so fluently" please keep on listening to what I say and don't compare my voice with that of a deaf born person. It is only 15 years ago that I became deafened."

Fortunately for Laurel and me, written English seemed to be a fairly universal language; however, note-taking at our session was on the overhead projector in Japanese.

In my presentation, I shared information about ALDA and read some of the anonymous written answers that had been collected at my ALDacon II workshop in response to the question, "What helped most?" Here are a couple of examples:

"When I lost my hearing 25 years ago, I was in my mid 20s. I had a young family, and this was a devastating event for me. There was very little help from others because they just didn't know what to do. My doctor said I would just have to "live with it." I found that keeping a journal and writing down my thoughts and feelings helped me very much. It was good therapy for me."

"The thing that helped most was having deaf and deafened role models. If deaf people can live happily without ever hearing, I could learn too. If deafened people could overcome the loss, I could too. Being in a support group helped me learn to deal with the loss and apply my coping skills to my deafness."

Following my talk, a number of people from several different countries approached me. Will ALDA become international? Will you add me to the mailing list? and Tell me more about ALDA. Since then, I have received a number of requests from Sweden, Norway, Finland, and Holland from deafened people who know English and who asked for a copy of our Tokyo presentation. Above all, they wanted to be on the ALDA mailing list.
Laurel Glass presented in Paris at a colloquium that focused on the culturally Deaf population. I think Judy Tingley and I may have been the only deafened persons in attendance. Laurel, and her French counterpart, M. Dauby of the Bureau of Coordination of Associations of the Deafened and Hearing Impaired presented on late deafened adults. Laurel raised three points:

1. Persons who become deaf as adults have needs, histories, and experiences that are dramatically different from those of persons who were born deaf or who learned sign language early in life.
2. Public or private rehabilitation agencies seem unaware of the range of needs or of the variety of assistance that would be appropriate for deafened adults.
3. The most useful resources are self-help groups such as ALDA.

M. Dauby shared the following:

“The population we are discussing includes those people who have normal intellectual and physical capabilities and who have established a normal system of social and emotional relationships. Suddenly, or progressively, these relationships disappear. Friends take their leave, contacts with colleagues become rare, even the family environment turns sour. Everything sinks into silence! In spite of their large numbers, their problems are often not recognized by the general public or even by health professionals or social workers.”

Roz Rosen, president of the National Association of the Deaf in America, talked about the politics of Deafness:

“Recognition of the right to be different and to assemble with one’s own kind has led to the establishment of many different groups within the deaf community. [ALDA was included as one such group, as was SHHH and the newly formed Cochlear Implants Association.] NAD has initiated action to start up an internal coalition of affiliates in order to gain a broader base of representation of Deaf America. Where do we go from here? Join with us, walk beside us, and be our partners toward a more progressive future where each person is accepted for him or herself.”

The implication of that statement for ALDA is, “You are accepted. Let us work together.”

This international experience reinforces the reality that the late deafened population is like a sleeping giant that is beginning to awaken and to ask for recognition. What is the message for ALDA?

1. Lay in a supply of foreign postage
2. Begin looking for foreign language translators for *ALDA News.*
3. Begin saving your money for ALDAcon IX or X in Helsinki or Tokyo.

There are still two problems. I didn’t learn how to write ALDA in Japanese, and I didn’t learn how to say ALDA in French, but when I find out, I’ll let you know.
The Adult Onset Hearing Loss Project is supported in part by the National Institute on Disability and Rehabilitation Research, Grant HI33A90003. Opinions expressed are those of the author and do not necessarily reflect those of the U.S. Department of Education.
Volunteerism and Advocacy

Karina Graham

Karina Graham, L.C.S.W., A.C.S.W., is a social worker who has been involved in the fields of deafness and mental health for 13 years. She is currently the Director of Thresholds Bridge for the Hearing Impaired, a psychiatric rehabilitation center for deaf adults. Karina has actively advocated for numerous mental health, substance abuse, and ALDA-related projects, and volunteered on various committees and boards related to deafness. She is also a therapist and consultant in private practice in Chicago. Of course, we know her best for her valiant marriage to Bill Graham, ALDA's Executive Director extraordinaire.

I was amazed when I was asked to give this morning's talk on volunteerism and advocacy. I must tell you from the start that I've had a love/hate relationship with this topic since my baptism into the field of social services over 10 years ago. I do not understand volunteerism. Never did.

My father was a union organizer during the 60s and 70s. He organized factories where people assembled lock parts and put wire together and such. I grew up going to picket lines, seeing rock fights and trucks being overturned (this is Chicago, you know). I saw men and women standing outside freezing in Chicago winters. When I asked my father why they were doing this, he replied, "They deserve a fair day's pay for a fair day's work." People deserve to earn money for the work they do. I had no notion of the more leisure-class concept of volunteerism. People in my neighborhood worked in hot factories with their hands all day, came home dead tired, ate, and fell asleep. If they volunteered anything, it was to go to the corner for a six-pack. No, volunteerism was for women who went to lots of luncheons and wore elaborate hats.

Then I went to social-work school and have been a social worker for 10 years in a country that doesn't like to admit it has a domestic agenda. It was eliminating social-work jobs before I even had a chance to apply for them. There was less government spending on social services, and when the going gets tough, well we can just pull ourselves up by our bootstraps. Yes, this is a nation in love with volunteerism. I was intrigued by President Bush's "Thousand Points of Light" program, which I interpreted as a way to get regular people to do social work without getting paid. My father would never approve.

I'll admit it. I don't like volunteerism. I don't believe anyone gets bonus points in heaven for donating time or money to charity. I don't want the viability of wonderful organizations like ALDA to depend on the benevolence of its members or solely on the whim of
contributors because whims change, members get tired. It simply isn't the way programs that change people's lives in the way ALDA has should be supported.

Then why have I spent a great portion of the past 10 years of my life engaged in volunteer activities? Why have I been on boards, lobbied in Springfield and Washington, written scores of letters, spoken for the cost of transportation, written proposals into the night, and called and talked and called and talked for so many years? Maybe because I've had to. I am not here today to talk about volunteerism from the standpoint of nobility, I am talking about volunteerism from the standpoint of necessity.

The first time I was called on to volunteer was in graduate school in 1980. I became aware of the appalling dearth of mental health services to deaf people. Nothing was being done while scores of deaf people were rotting in snake pit institutions hidden in the rolling central Illinois fields. Something had to be done. I was called upon by a group of lawyers to assist in the research involved in a suit against the state on behalf of one of these deaf people. I gladly agreed to participate and was quickly assigned to my particular volunteer task. I was to assess all of the in- and out-patient mental health programs in the United States, analyze the components and effectiveness of their programs, estimate the number of deaf mentally ill people in the state of Illinois, and finally, design an ideal program for the deaf mentally ill man in question. This wasn't funny. This was more work than I had anticipated doing in all my classes that quarter. this was also undoubtedly the real thing. The result of the law suit was favorable, and I had my first taste of the reality that we really can change things for the better. Now I am an addict.

I have also been fascinated by the enormous amounts of volunteer work and advocacy done by you, ALDA members. The dedication and enthusiasm among your ranks is unparalleled anywhere. Every bit of work you do is done without tangible reward. I have watched you patiently explain late-onset deafness to the most ignorant of people. I have watched you tirelessly answer letters from frightened deaf people isolated in small towns. I have watched you eloquently tell your stories to yet another newspaper to assure they print the true facts about late-deafness. I have watched you work for hours after your regular jobs to assure the newsletter was perfect or the conference menu was just right. You have been magnificent. But I guess you have to do this, don't you? No one else is going to do this for you.

I also know you haven't come by this easy. I remember accompanying Bill to an event where he was to give a presentation on deafness. I finally learned what the term "beads of sweat" meant. I had never seen a person so completely beside himself over giving a talk to a few people. There were, of course, elements of concern I did not understand at the time. Would he understand the questions asked of him? Would his voice carry? Did he know enough about deafness to make a strong statement? Of course, Bill had a marvelous message and the questions that he did not understand he asked for clarification or maybe made up the answers, but nonetheless the event was a smashing success because Bill stuck his neck out to make a difference.

I remember suggesting to Bill several years ago that he advocate for himself on the job. He needed interpreters and a flashing light for the phone and other things. I also remember him looking at me as if I just asked him to spontaneously levitate. He did not seem to have a clue as to how one would go about advocating for these unusual things. I suggested he start by simply asking. Well, several years later he has those things plus regular days off for some of his volunteer work with Gallaudet. Bill has gotten good at asking for things, and that is the heart of advocacy. This is what we need to do.
Remember, take it all matters, everything from explaining to a friend how to speak to his deafened father to lobbying Washington for the passage of the Americans with Disabilities Act, from writing a feature for the local newsletter to giving a presentation to court reporters on working with late-deafened adults. Whether we get paid for it or not—and we are actively working to see that someday someone does get paid for ALDA work—it’s what we do to assure that progress toward the understanding of the unique aspects of acquired deafness happens. Everything that moves us toward those ends counts.

ALDA is an organization in its infancy. The future of ALDA is in your hands. Don’t be divided by minor internal squabbles. Work hard, work cooperatively, and always remember your goal of providing a safe haven of hope, information, and support for late-deafened adults because that is what is really important.

Again, my hat goes off to all of you. You have created an organization that many people call "home". I particularly want to congratulate the winners of this year’s special ALDA awards. To win an award for special work in this group where such a tremendous amount of special work abounds is some achievement.
Section Two:

Coping
Facing Deafness: An International Perspective

Roy E. Miller

Professor Miller received his B.S. degree from Bradley University in 1961, his M.A. degree from the University of Pittsburgh in 1965, and his Ph.D. degree from the University of Illinois in 1971. He joined the faculty of Southern Illinois University at Carbondale in 1967, and has taught there ever since. He now holds a joint appointment as an Associate Professor of Political Science and an Associate Scientist in the Office of Institutional Research. Professor Miller was deafened in 1987 due to the surgical removal of bilateral acoustic neuromas. He is currently serving as the president of the Association of Late-Deafened Adults (ALDA), the president of the Association of Late-Deafened Adults in Southern Illinois (ALDA-SI), and the president of the Southern Illinois Center for Independent Living (SICIL). Professor Miller is a member of Phi Eta Sigma, Pi Kappa Delta, Pi Sigma Alpha, Omicron Delta Kappa, and Phi Kappa Phi national honorary fraternities, as well as Who's Who in American Colleges and Universities. His professional memberships include the American Political Science Association, Midwest Political Science Association, American Statistical Association, International Communication Association, Illinois Political Science Association, and the Illinois Association for Institutional Research. Professor Miller has published in such journals as "Teaching Political Science," "Experimental Study of Politics," "Political Behavior,\" "International Political Science Review,\" and the "American Journal of Otology." He is also the author of over thirty professional papers, a chapter in the "Handbook of Political Communication," the ALDA National By-Laws, the ALDA Chapter By-Laws, the ALDA NOTES series, and a frequent contributor to the ALDA News.

Introduction

At times the trauma of becoming deaf can be so overwhelming that we feel as if nobody else really understands or has suffered the same sensory loss ever before. For all of us late-deafened adults, becoming deaf is a very personal experience. Almost without exception, all of our working colleagues, friends, family members, and other loved ones are hearing persons. They do not, and cannot, directly share the experience with us. Coping with the psychological transition of becoming a late-deafened adult is something, which in a very major sense, we must do all by ourselves. Unfortunately, all too often the necessarily private nature of this psychological experience can result in the feeling of total isolation. In fact, at times we may even feel that we are the only late-deafened adult in the entire world.
Of course, if we stop to really think about it, we know that this feeling of being all alone has no basis in fact. Persons who become late-deafened adults are everywhere. Quite possibly there may be another one of us just down the street a few houses, or in the next block, or down the road a couple of miles. Quite probably there are some others just like us scattered around town, or in our part of the county. And most definitely there are a great many other late-deafened adults located from coast to coast in every state of our nation.

But, late-deafness is not something that begins and ends at our borders. Rather, it is a world-wide phenomenon, existing in every country around the globe. And late-deafened adults everywhere share the common experience of having become deaf after they have developed speech and language skills within their own linguistic culture, and thus having to struggle and cope with the same communication problems.

The global incidence of late-deafened adults makes one wonder how people from other countries face the communication problems resulting from their sensory loss. More specifically, it brings to mind the question of what support services are provided in other countries to help persons who are late-deafened cope with their communication difficulties. And, of course, this leads to the query of how do support services in the USA compare to those available in other countries.

This paper will, in a very small way, address these questions, and in doing so hopes to encourage the reader to think about the problems of facing deafness from a global perspective. This paper has basically two objectives. First, I want to share some very specific details about several programs and organizations that provide support for people who are deaf or hard-of-hearing in two foreign countries that I had the pleasure of visiting during the summer of 1991, namely, Great Britain (England and Scotland) and Bulgaria. Second, I want to share some general information about the support services for persons who are deaf or hard-of-hearing in several countries scattered around the world. The countries include the USA, Canada, Great Britain, Bulgaria, the Netherlands, Israel, South Korea, and New Zealand.

The data for this paper were compiled by means of a small survey of international subscribers to DEAF-L during the fall of 1991. As a result, the data is only as accurate as the understandings of the DEAF-L subscribers who participated in the survey. DEAF-L is an unmoderated electronic forum for the discussion of any and all matters pertaining to deafness. Anyone can subscribe to DEAF-L who has access to either BITNET or the INTERNET world-wide computer networks.

An In-Depth Look At Support Services
For Persons Who Are Deaf Or Hard-Of-Hearing In Great Britain

Great Britain is very much like the USA when it comes to support services and organizations that are available for persons who are deaf or hard-of-hearing. There is a tremendous variety of such services and organizations, with many of them having been around for a long time. No attempt will be made here to discuss all of those services and organizations. Rather, only a few will be highlighted as examples.
1. IBM United Kingdom Trust  
   Support Centre for People with Disabilities  
   P.O. Box 31  
   Birmingham Road  
   Warwick CV34 5JL England  
   Telephone: 0926 332525  
   Freephone: 0800 269545  

   The IBM Support Centre for People with Disabilities in Warwick is the counterpart in Great Britain to the IBM Support Center for Persons with Disabilities located in the USA in Atlanta, Georgia. As such, it is a research and development, information, and marketing center for telecommunications technology developed and distributed by IBM for persons with disabilities.

2. Visual Language Centre  
   School of Languages and European Studies  
   Wolverhampton Polytechnic  
   Stafford Street  
   Wolverhampton WV1 1SB  
   England  
   Telephone: 0902 322353 (Voice/TDD)  
   Fax: 0902 250150  

   A Polytechnic in Great Britain is similar to a Junior College here in the USA. The Visual Language Centre at Wolverhampton Polytechnic was established in 1991. Its main areas are: (a) research into the use of new technology and new training methods as they relate to sign language instruction, (b) the provision of both full-time and part-time training courses in British Sign Language, and (c) providing access for persons who are deaf or hard-of-hearing to higher education.

3. Council for the Advancement of Communication with Deaf People  
   Pelaw House  
   School of Education  
   University of Durham  
   Durham DH1 1TA  
   England  
   Telephone: 091 374 3607  

   The Council for the Advancement of Communication with Deaf People (CACDP) was formed in 1980 and is comprised of deaf and hearing representatives from national organizations concerned with deafness. Its purpose is to improve communication between deaf and hearing people and thus advance the welfare, status, and opportunities of those who are deaf in a hearing world. This aim is achieved by the development of training and examinations in communication skills and by administering a register of qualified sign language interpreters. The CACDP does not advocate one method of communication in preference to any other, but rather seeks to meet the needs of all who are deaf. It administers examinations in not only sign language skills, but also in oral interpreting (lipspeaking) and communication with deaf-blind persons. The CACDP is the counterpart in Great Britain of the Registry of Interpreters for the Deaf (RID) in the USA.
4. British Deaf Association  
38 Victoria Place  
Carlisle  
Cumbria  CA1 1HU  
England  
Telephone: 0228 48844 (Voice)  
0228 28719 (TDD)  
Fax: 0228 41420  
The British Deaf Association (BDA) was founded in 1890. It came into being as a direct result of the failure of an 1889 Royal Commission on the education of deaf children to consult persons who were Deaf and as an indirect response to the famous Milan Conference of 1880. The Milan Conference was attended primarily by hearing teachers of deaf children, and it passed a resolution banning the use of sign languages throughout the world in deaf education. The broad aims of the BDA are to advance and protect the interests of Deaf people and to help them develop pride, identity, leadership qualities, and awareness of their rights and responsibilities – thereby strengthening their own community and enabling them to take their places as full members of the wider national community. The BDA has over 18,000 members and features a program of:  

- Sign Language Services  
- Advocacy and Casework Services  
- Education and Training Services  
- Youth Services  
- Sport and Leisure Services  
- Information Services  
The BDA is the counterpart in Great Britain of the National Association of the Deaf (NAD) in the USA.

5. The Scottish Association for the Deaf  
Moray House College  
Holyrood Road  
Edinburgh  EH8 8AQ  
Scotland  
Telephone: 031 557 0591 (Voice)  
031 557 6922 (TDD)  
Fax: 031 557 6624  
The Scottish Association for the Deaf is the only national support group for persons who are hearing impaired in all of Scotland. It was established in 1927, and since then it has been recognized as having singular responsibility for coordinating the activities of all organizations working with and for deaf people of all ages in Scotland. Its mission includes promoting the welfare of all persons with a hearing loss, including persons who are deaf, deafened, or hard-of-hearing.
6. The Royal National Institute for the Deaf
105 Gower Street
London WC1E 6AH
England
Telephone: 01 387 8033

The Royal National Institute for the Deaf (RNID) is a voluntary organization representing the interests of persons who are deaf, deaf-blind, or hard-of-hearing. It attempts to ensure that their needs are properly recognized by both government and the general public and that facilities and services for deaf people are continually improved. In addition, the RNID provides a wide range of direct services for deaf people and professionals dealing with deafness. It leads the way in medical and scientific research on deafness and on technological aids for deaf people.

7. The Centre for Deaf Studies
University of Bristol
22 Berkeley Square
Bristol BS8 1HF
England
Telephone: 0272 303030 (Voice)
0272 251370 (TDD)
Fax: 0272 251537

The Centre for Deaf Studies at Bristol University has as its aim to provide a focal point for deaf people in research, to offer training facilities in the field of deafness, and to develop and apply new ideas and new materials in a way that will prove beneficial to deaf people and those around them. The centre is concerned with all ages and all types of hearing problems and the ways in which these affect people educationally, socially and psychologically as well as in their language and communication. The centre works with persons who are born deaf and also with persons who lose their hearing later in life.

Great Britain has many other organizations that provide services for persons who are deaf or hard-of-hearing. For reference purposes, a few of them are listed here.

- Association of Teachers of Lipreading to Adults
- British Association for the Hard-of-Hearing
- Commonwealth Society for the Deaf
- Deaf Microcomputer Users Group
- Hearing Aid Council
- Hearing Dogs for the Deaf
- Hearing Impaired Teachers Group
- National Centre for Cued Speech
- Link the British Centre for Deafened People
- National Association of Deafened People
- National Aural Group
- National Deaf/Blind Helpers League
- National Subtitling Library for Deaf People
- Working Party on Signed English

So, as you can see, Great Britain is very much like the USA with many support groups representing all of the different sectors of the deaf, deafened, or hard-of-hearing population. Just as the language, culture, customs, and laws are very similar in Great
Britain to those in the USA, so too there is great similarity between the organizational infrastructure that provides support for persons who are deaf or hard-of-hearing.

An In-Depth Look At Support Services For Persons Who Are Deaf Or Hard-Of-Hearing In Bulgaria

During the summer of 1991, I was also privileged to visit Bulgaria. This was my first visit to an Eastern European country since the fall of the Iron Curtain and the near total demise of communism as a political system in that area of the world. My primary reason for visiting Bulgaria was to present a paper at the First Bulgarian-American Law Days Conference, which was held in Varna, on the coast of the Black Sea. However, during my stay in the country I had the opportunity to visit at the Union of the Deaf in Bulgaria, which is located in the capital city of Sophia.

As Bulgaria was a communist country for nearly fifty years, it was to be expected that all social services would be highly centralized. Accordingly, it came as no surprise to learn that the Union of the Deaf in Bulgaria is effectively the only national support organization for persons who are deaf in Bulgaria.

The Union of the Deaf in Bulgaria is a voluntary organization that is educational, economic, and social in character and provides services to both people who are deaf and people with a profound hearing loss. A total of about 6,000 people are now organized in the Union of the Deaf in Bulgaria. Approximately 2,800 of them work in the production enterprises of the 13 regional societies of the Union of the Deaf bearing the common name 'Tih Troid' (Quiet Work).

Each of the 13 regional societies not only has its own industry that specializes in the making of furniture, clothes, and so forth, but each society also has its own school, medical facility, and housing and maintains its own cultural, educational, and sports activities. In addition to the regional facilities, however, there are national centers for Rehabilitation of Hearing and Speech in both Sophia and Plovdiv, and rehabilitation laboratories for children up to the age of three located in the cities of Varna, Gorna, Oryahovitsa, and Pleven.

The Union of the Deaf has three "holiday houses" of its own, one located on the Black Sea, one in the mountains, and one at a mineral springs spa. These holiday houses provide 2,500 beds during the peak vacation season. During the off season, they provide free vacations for deaf persons who are aged or sick.

The Union of the Deaf in Bulgaria has been very active in the international activities of the world-wide deaf community. For example, Bulgaria hosted the 8th World Congress of the World Federation of the Deaf and will host the 17th World Summer Games for the Deaf in Sophia in 1993.

The socialist revolution in 1944 found Bulgaria's deaf citizens in a very bad situation. They were living in complete social isolation, steeped in economic and physical misery and ignorance. At that time there was only one school for deaf children in the whole country, and, of course, it could not educate even a tiny fraction of the deaf children of school age. Seemingly life for persons who were deaf or profoundly hard-of-hearing in Bulgaria under
the communist regime improved tremendously. It can fairly be said that under the communist political system there were no deaf people in all of Bulgaria who were either illiterate or unemployed. In fact, in recent times life in Bulgaria was pretty good for people who were deaf, and this was more or less typical of all Eastern European countries. However, with the recent changes to a market economy, I fear that life for persons who are deaf under the new democratic system in Bulgaria can only become economically worse than it was under the communist regime – at least for some period of time to come.

Support Services For Persons Who Are Deaf Or Hard-Of-Hearing:
A Partial World View

Thus far I have taken an in-depth look at support programs and organizations for persons who are deaf or hard-of-hearing in one of the oldest democracies in the world (Great Britain), and in one of the newly emerging democracies of Eastern Europe that is striving to change its social and political institutions from those that were developed under nearly a half a century of communist rule (Bulgaria). I would now like to give a summary overview of basic support services available for persons who are deaf or hard-of-hearing in a variety of countries scattered around the globe. My purpose in presenting this information is to facilitate a comparison of the communication challenges of facing deafness in the USA versus a few other countries from the international community.

It might help to begin by giving the approximate total population of the countries involved. Table 1 shows the extreme differences in size among the countries, which range from the very large USA (with a population of about 238 million) to the very small New Zealand (with a population of about 3 million).

<table>
<thead>
<tr>
<th>Country</th>
<th>Population</th>
</tr>
</thead>
<tbody>
<tr>
<td>USA</td>
<td>238 million</td>
</tr>
<tr>
<td>Canada</td>
<td>25 million</td>
</tr>
<tr>
<td>Great Britain</td>
<td>56 million</td>
</tr>
<tr>
<td>Netherlands</td>
<td>14 million</td>
</tr>
<tr>
<td>Bulgaria</td>
<td>9 million</td>
</tr>
<tr>
<td>Israel</td>
<td>4 million</td>
</tr>
<tr>
<td>South Korea</td>
<td>42 million</td>
</tr>
<tr>
<td>New Zealand</td>
<td>3 million</td>
</tr>
</tbody>
</table>


The principal support for persons who are deaf or hard-of-hearing is, of course, being adequately employed, for it is primarily a person's economic status that often enables the individual to obtain other necessary support services. From Table 2 we see that whereas the economic status of people who are deaf or hard-of-hearing is about average in Great Britain, the Netherlands, and Bulgaria, in most of the countries, including the USA, it is
probably the case that the economic status of persons who are hearing impaired is below average.

Table 2. Economic Status of Persons Who Are Deaf Or Hard-Of-Hearing

<table>
<thead>
<tr>
<th>Country</th>
<th>Average</th>
<th>Below Average</th>
</tr>
</thead>
<tbody>
<tr>
<td>USA</td>
<td></td>
<td>X</td>
</tr>
<tr>
<td>Canada</td>
<td></td>
<td>X</td>
</tr>
<tr>
<td>Great Britain</td>
<td></td>
<td>X</td>
</tr>
<tr>
<td>Netherlands</td>
<td></td>
<td>X</td>
</tr>
<tr>
<td>Bulgaria</td>
<td></td>
<td>X</td>
</tr>
<tr>
<td>Israel</td>
<td></td>
<td>X</td>
</tr>
<tr>
<td>South Korea</td>
<td></td>
<td>X</td>
</tr>
<tr>
<td>New Zealand</td>
<td></td>
<td>X</td>
</tr>
</tbody>
</table>

An adequate economic base can ensure that persons who are deaf or hard-of-hearing get the opportunity to overcome their communication difficulties only with the complementary support of the legal system. Table 3 presents information regarding the question of whether it is illegal in the various countries to discriminate against a person simply because they are deaf or hard-of-hearing. Such discrimination only recently became illegal in most circumstances in the USA with the passage of the Americans with Disabilities Act (ADA), but it is still the case that many countries around the globe do not have laws that make such discrimination illegal.

Table 3. Is It Illegal To Discriminate Against Persons Who Are Deaf Or Hard-Of-Hearing?

<table>
<thead>
<tr>
<th>Country</th>
<th>Yes</th>
<th>No</th>
</tr>
</thead>
<tbody>
<tr>
<td>USA</td>
<td>X</td>
<td></td>
</tr>
<tr>
<td>Canada</td>
<td>X</td>
<td></td>
</tr>
<tr>
<td>Great Britain</td>
<td>X</td>
<td>X</td>
</tr>
<tr>
<td>Netherlands</td>
<td>X</td>
<td></td>
</tr>
<tr>
<td>Bulgaria</td>
<td>X</td>
<td></td>
</tr>
<tr>
<td>Israel</td>
<td>X</td>
<td></td>
</tr>
<tr>
<td>South Korea</td>
<td>X</td>
<td></td>
</tr>
<tr>
<td>New Zealand</td>
<td>X</td>
<td></td>
</tr>
</tbody>
</table>
The opportunity to enjoy the benefits of obtaining a higher education may be one of the most important supports for persons who are deaf or hard-of-hearing in any country. Table 4 presents a summary picture of the types of support services available for persons who are deaf or hard-of-hearing in colleges and universities in the different countries. In two of the countries (USA and Canada), the support services are provided directly by the institutions. In some countries (Great Britain and Israel), the student is given financial assistance specifically for the purpose of purchasing support services on the open market. But in many of the countries there is no special support provided to students in higher education who are deaf or hard-of-hearing.

Table 4. Support Services Available In Higher Education For Persons Who Are Deaf Or Hard-Of-Hearing

<table>
<thead>
<tr>
<th>Country</th>
<th>Services</th>
</tr>
</thead>
<tbody>
<tr>
<td>USA</td>
<td>Interpreters, FM Loops, Notetakers, typists</td>
</tr>
<tr>
<td>Canada</td>
<td>Interpreters, FM Loops, Notetakers</td>
</tr>
<tr>
<td>Great Britain</td>
<td>Special Financial Assistance</td>
</tr>
<tr>
<td>Netherlands</td>
<td>Nothing</td>
</tr>
<tr>
<td>Bulgaria</td>
<td>Nothing</td>
</tr>
<tr>
<td>Israel</td>
<td>Special Financial Assistance</td>
</tr>
<tr>
<td>South Korea</td>
<td>Nothing</td>
</tr>
<tr>
<td>New Zealand</td>
<td>Nothing</td>
</tr>
</tbody>
</table>

The availability of qualified interpreters is a vital support service for those persons who are deaf and rely on the use of sign language for daily communication. Table 5 shows that in most countries it is sometimes difficult for persons who are deaf or hard-of-hearing to obtain the services of a qualified interpreter, and that in some countries (Great Britain, Netherlands, South Korea) it is always difficult to find qualified interpreters.

Table 5. Is It Difficult To Get An Interpreter For Persons Who Are Deaf Or Hard-Of-Hearing

<table>
<thead>
<tr>
<th>Country</th>
<th>Always</th>
<th>Sometimes</th>
</tr>
</thead>
<tbody>
<tr>
<td>USA</td>
<td></td>
<td>X</td>
</tr>
<tr>
<td>Canada</td>
<td></td>
<td>X</td>
</tr>
<tr>
<td>Great Britain</td>
<td>X</td>
<td></td>
</tr>
<tr>
<td>Netherlands</td>
<td>X</td>
<td></td>
</tr>
<tr>
<td>Bulgaria</td>
<td>X</td>
<td></td>
</tr>
<tr>
<td>Israel</td>
<td></td>
<td>X</td>
</tr>
<tr>
<td>South Korea</td>
<td>X</td>
<td></td>
</tr>
<tr>
<td>New Zealand</td>
<td></td>
<td>X</td>
</tr>
</tbody>
</table>
Similarly, for persons who are deaf who depend on sign language interpreters as a communications interface, the quality of those interpreters determines to a large degree the quality of the communications experience. Table 6 indicates that while sign language interpreters are tested and certified by some organization in most countries, there is still no effort made to ensure the quality of interpreters in some countries (namely, Canada, Bulgaria, and New Zealand).

<table>
<thead>
<tr>
<th>Country</th>
<th>Yes</th>
<th>No</th>
</tr>
</thead>
<tbody>
<tr>
<td>USA</td>
<td>X</td>
<td></td>
</tr>
<tr>
<td>Canada</td>
<td></td>
<td>X</td>
</tr>
<tr>
<td>Great Britain</td>
<td>X</td>
<td></td>
</tr>
<tr>
<td>Netherlands</td>
<td>X</td>
<td></td>
</tr>
<tr>
<td>Bulgaria</td>
<td></td>
<td>X</td>
</tr>
<tr>
<td>Israel</td>
<td>X</td>
<td></td>
</tr>
<tr>
<td>South Korea</td>
<td>X</td>
<td></td>
</tr>
<tr>
<td>New Zealand</td>
<td></td>
<td>X</td>
</tr>
</tbody>
</table>

In recent years there has been a greater realization of the fact that many persons who are deaf or hard-of-hearing cannot benefit from the services of sign language interpreters simply because these people do not sign. Many such persons are late-deafened adults and require some type of captioning service for effective communication. Table 7 shows that while the availability of real-time captioners is beginning to take hold in North America and Western Europe, it is not yet a service that is available in much of the world.

<table>
<thead>
<tr>
<th>Country</th>
<th>A Few</th>
<th>Not Yet</th>
</tr>
</thead>
<tbody>
<tr>
<td>USA</td>
<td>X</td>
<td></td>
</tr>
<tr>
<td>Canada</td>
<td>X</td>
<td></td>
</tr>
<tr>
<td>Great Britain</td>
<td>X</td>
<td></td>
</tr>
<tr>
<td>Netherlands</td>
<td>X</td>
<td></td>
</tr>
<tr>
<td>Bulgaria</td>
<td></td>
<td>X</td>
</tr>
<tr>
<td>Israel</td>
<td></td>
<td>X</td>
</tr>
<tr>
<td>South Korea</td>
<td></td>
<td>X</td>
</tr>
<tr>
<td>New Zealand</td>
<td></td>
<td>X</td>
</tr>
</tbody>
</table>

For many persons who are deaf or hard-of-hearing, the inability to use the telephone presents major social, familial, and occupational limitations upon their lives. With the advent of the modern Telecommunications Device for the Deaf (TDD), some of the familial and social limitations were erased. Although Table 8 indicates that TDDs are now commonly available in many countries around the world, they still are a relatively scarce resource in some countries (namely, Bulgaria and South Korea).
Table 8. Are There TDDs Commonly Available For Persons Who Are Deaf Or Hard-Of-Hearing

<table>
<thead>
<tr>
<th>Country</th>
<th>Yes</th>
<th>No</th>
<th>Comment</th>
</tr>
</thead>
<tbody>
<tr>
<td>USA</td>
<td>X</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Canada</td>
<td>X</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Great Britain</td>
<td>X</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Netherlands</td>
<td>X</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Bulgaria</td>
<td></td>
<td>X</td>
<td>(English language machines only)</td>
</tr>
<tr>
<td>Israel</td>
<td>X</td>
<td></td>
<td></td>
</tr>
<tr>
<td>South Korea</td>
<td></td>
<td>X</td>
<td></td>
</tr>
<tr>
<td>New Zealand</td>
<td></td>
<td>X</td>
<td></td>
</tr>
</tbody>
</table>

A TDD is only useful if a person knows the telephone number of the party being called. Its usefulness as a support service for persons who are deaf or hard-of-hearing can be enhanced greatly if there is a TDD telephone directory available that lists the phone numbers for persons and businesses that have TDDs. Table 9 clearly shows that while national TDD telephone directories are available in a few countries (the USA, Canada, and Great Britain), they are not yet available in most parts of the world.

Table 9. Is There A National TDD Telephone Directory Available?

<table>
<thead>
<tr>
<th>Country</th>
<th>Yes</th>
<th>No</th>
</tr>
</thead>
<tbody>
<tr>
<td>USA</td>
<td>X</td>
<td></td>
</tr>
<tr>
<td>Canada</td>
<td>X</td>
<td></td>
</tr>
<tr>
<td>Great Britain</td>
<td>X</td>
<td></td>
</tr>
<tr>
<td>Netherlands</td>
<td></td>
<td>X</td>
</tr>
<tr>
<td>Bulgaria</td>
<td></td>
<td>X</td>
</tr>
<tr>
<td>Israel</td>
<td></td>
<td>X</td>
</tr>
<tr>
<td>South Korea</td>
<td></td>
<td>X</td>
</tr>
<tr>
<td>New Zealand</td>
<td></td>
<td>X</td>
</tr>
</tbody>
</table>

Conversational speech may occur at a rate as high as 250 words per minute. On the other hand, TDDs transmit at a rate of roughly 60 words per minute (300 Baud). As a result it may take four times as long to say the same thing using a TDD as it does in normal telephone conversation. This, of course, means that persons who are deaf or hard-of-hearing and must use TDDs are severely penalized in the amount they must pay for telephone services. To partially offset this structural characteristic of TDDs, in some countries TDD users pay special reduced telephone rates (at least for long distance calls). Table 10 shows that while such discounted rates are available in a few countries (the USA, Canada, and Great Britain), this form of support for persons who are deaf or hard-of-hearing is not available in most countries around the world.
Table 10. Do TDD Users Pay Reduced Telephone Rates?

<table>
<thead>
<tr>
<th>Country</th>
<th>Yes</th>
<th>No</th>
</tr>
</thead>
<tbody>
<tr>
<td>USA</td>
<td>X</td>
<td></td>
</tr>
<tr>
<td>Canada</td>
<td>X</td>
<td></td>
</tr>
<tr>
<td>Great Britain</td>
<td>X</td>
<td></td>
</tr>
<tr>
<td>Netherlands</td>
<td></td>
<td>X</td>
</tr>
<tr>
<td>Bulgaria</td>
<td></td>
<td>X</td>
</tr>
<tr>
<td>Israel</td>
<td></td>
<td>X</td>
</tr>
<tr>
<td>South Korea</td>
<td></td>
<td>X</td>
</tr>
<tr>
<td>New Zealand</td>
<td></td>
<td>X</td>
</tr>
</tbody>
</table>

The usefulness of TDDs is enhanced if there is a special operator available to assist persons making calls with TDDs. Such an operator can facilitate collect and credit card calling, as well as person-to-person calls and calls billed to separate numbers. Table 11 indicates that while a special TDD operator is available in some countries (the USA, Canada, and the Netherlands), that support service for persons who are deaf or hard-of-hearing is not yet available throughout most of the world.

Table 11. Is There A Special Telephone Operator Available To Assist With TDD Calls?

<table>
<thead>
<tr>
<th>Country</th>
<th>Yes</th>
<th>No</th>
</tr>
</thead>
<tbody>
<tr>
<td>USA</td>
<td>X</td>
<td></td>
</tr>
<tr>
<td>Canada</td>
<td>X</td>
<td></td>
</tr>
<tr>
<td>Great Britain</td>
<td></td>
<td>X</td>
</tr>
<tr>
<td>Netherlands</td>
<td></td>
<td>X</td>
</tr>
<tr>
<td>Bulgaria</td>
<td></td>
<td>X</td>
</tr>
<tr>
<td>Israel</td>
<td></td>
<td>X</td>
</tr>
<tr>
<td>South Korea</td>
<td></td>
<td>X</td>
</tr>
<tr>
<td>New Zealand</td>
<td></td>
<td>X</td>
</tr>
</tbody>
</table>

TDDs cannot be used to communicate directly with anyone who does not have a TDD, which is probably the situation for more than 99 percent of all telephone users. Accordingly, in order to enable persons who are deaf or hard-of-hearing to telecommunicate with the vast majority of the population who are hearing persons, as well as other deaf or hard-of-hearing persons who do not have TDDs but have a hearing person in their household, the telephone relay provides a critical support service. Table 12 shows that while telephone relay services are being put in place in many countries of the world, they are far too often still geographically fragmented existing only in some cities, states, or provinces. Even worse, many countries (Bulgaria, Israel, and South Korea) do not yet have any relay services.
Table 12. Are There Any Telephone Relay Services Available?

<table>
<thead>
<tr>
<th>Country</th>
<th>Yes</th>
<th>No</th>
<th>Comment</th>
</tr>
</thead>
<tbody>
<tr>
<td>USA</td>
<td>X</td>
<td></td>
<td>(In most of the states)</td>
</tr>
<tr>
<td>Canada</td>
<td>X</td>
<td></td>
<td>(In all provinces)</td>
</tr>
<tr>
<td>Great Britain</td>
<td>X</td>
<td></td>
<td>(A national service)</td>
</tr>
<tr>
<td>Netherlands</td>
<td>X</td>
<td></td>
<td>(A national service)</td>
</tr>
<tr>
<td>Bulgaria</td>
<td>X</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Israel</td>
<td>X</td>
<td></td>
<td></td>
</tr>
<tr>
<td>South Korea</td>
<td>X</td>
<td></td>
<td>(In some cities)</td>
</tr>
<tr>
<td>New Zealand</td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

Over the past four decades television has grown to become the primary source of both entertainment and information for many people around the world. However, during that same period it has become little more than an additional source of frustration for many persons who are deaf or hard-of-hearing. In recent years, however, the development of closed-captioned television programming has allowed the entertainment and informational benefits of television to be enjoyed by many persons who are deaf or hard-of-hearing. Table 13 shows that the availability of closed-captioned TV programming varies tremendously around the world from as much as 200 hours per week in the USA to effectively none in countries such as Bulgaria and South Korea.

Table 13. Approximate Hours Per Week Of Closed Caption TV Available?

<table>
<thead>
<tr>
<th>Country</th>
<th>Hours/Week</th>
</tr>
</thead>
<tbody>
<tr>
<td>USA</td>
<td>200</td>
</tr>
<tr>
<td>Canada</td>
<td>70</td>
</tr>
<tr>
<td>Great Britain</td>
<td>25</td>
</tr>
<tr>
<td>Netherlands</td>
<td>21</td>
</tr>
<tr>
<td>Bulgaria</td>
<td>0</td>
</tr>
<tr>
<td>Israel</td>
<td>15</td>
</tr>
<tr>
<td>South Korea</td>
<td>0</td>
</tr>
<tr>
<td>New Zealand</td>
<td>15</td>
</tr>
</tbody>
</table>

Like any minority in society, life is enriched for persons who are deaf or hard-of-hearing if a primary entertainment medium in that society (television) includes some programming that is produced especially for members of that minority. Table 14 indicates that while there are a few countries that have special TV shows for deaf people (USA, Canada, Great Britain), most of the world does not yet provide this kind of societal support.
Table 14. Are There Special TV Shows For Persons Who Are Deaf Or Hard-Of-Hearing?

<table>
<thead>
<tr>
<th>Country</th>
<th>Yes</th>
<th>No</th>
</tr>
</thead>
<tbody>
<tr>
<td>USA</td>
<td>X</td>
<td></td>
</tr>
<tr>
<td>Canada</td>
<td>X</td>
<td></td>
</tr>
<tr>
<td>Great Britain</td>
<td>X</td>
<td></td>
</tr>
<tr>
<td>Netherlands</td>
<td>X</td>
<td></td>
</tr>
<tr>
<td>Bulgaria</td>
<td>X</td>
<td></td>
</tr>
<tr>
<td>Israel</td>
<td>X</td>
<td></td>
</tr>
<tr>
<td>South Korea</td>
<td>X</td>
<td></td>
</tr>
<tr>
<td>New Zealand</td>
<td>X</td>
<td></td>
</tr>
</tbody>
</table>

In recent years, the VCR (video cassette recorder) used in conjunction with a closed-caption decoder and a television set has provided a new medium of communication for persons who are deaf or hard-of-hearing. The rapid expansion in the availability of closed-caption videotapes has enabled persons who are deaf to enjoy home viewing of everything from old movie classics, to relatively new movies, to sign language instruction. However, Table 15 reminds us that closed-caption videos are still not available in some parts of the world.

Table 15. Are There Closed-Caption Videos Available?

<table>
<thead>
<tr>
<th>Country</th>
<th>Yes</th>
<th>No</th>
<th>Comment</th>
</tr>
</thead>
<tbody>
<tr>
<td>USA</td>
<td>X</td>
<td></td>
<td>(Lots available)</td>
</tr>
<tr>
<td>Canada</td>
<td>X</td>
<td></td>
<td>(Lots, but not in French)</td>
</tr>
<tr>
<td>Great Britain</td>
<td>X</td>
<td></td>
<td>(Some available)</td>
</tr>
<tr>
<td>Netherlands</td>
<td>X</td>
<td></td>
<td>(Lots available)</td>
</tr>
<tr>
<td>Bulgaria</td>
<td>X</td>
<td></td>
<td>(But almost all have</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td>Hebrew subtitles)</td>
</tr>
<tr>
<td>Israel</td>
<td>X</td>
<td></td>
<td>(Some available)</td>
</tr>
<tr>
<td>South Korea</td>
<td>X</td>
<td></td>
<td></td>
</tr>
<tr>
<td>New Zealand</td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

Conclusion

Clearly there is much variation in the different countries around the world with respect to the support services available for persons who are deaf or hard-of-hearing. But, as in so many things, one can fairly safely say that the services available for persons who are deaf or hard-of-hearing are greater in number and more abundant in the USA and Canada than anywhere else in the world.

I should like to leave you with just one more thought. For many of us who are late-deafened, when we first became deaf we felt like we were all alone in this world. Then perhaps we discovered another "one of us," another kindred spirit who had faced all of the same communication challenges resulting from becoming deaf. Then perhaps we discovered ALDA and learned that there were many others who had undergone the same experience, in our city, state, and nation.
Now, I hope that I have managed to increase your awareness of the fact that deafness knows no geographical nor national boundaries. There are many, many other deafened persons just like us all around the world, and their support services are all too often vastly inferior when compared to those that we enjoy here in the USA.

Certainly there's a great multitude of people around the world with different racial, linguistic, social, economic, religious, political, and cultural backgrounds – but all living with the same problems of adjusting to late-deafness. Probably they're much in need of a helping hand, even more so than here in the USA. Perhaps they're just waiting for the family fellowship and support that typifies ALDA to spread its magic, develop an international face, and transform ALDA-Nation into ALDA-World. And as I think about it, that's not a bad idea at all!
You, Your Mind & Body: A Winning Team In Facing Deafness

Gayle McCullough

Gayle McCullough is a late-deafened adult from Sacramento, California where she is President of ALDA Sacramento. Gayle is an award winning artist and the art director for the State Department of Social Services. When Gayle became deafened, she applied her creativity to learning about deafness, utilizing the resources of the State Office of Deaf Access she developed a team of people who together delved into all aspects of hearing impairment, focusing on legal, educational and medical aspects of hearing loss. She has been instrumental in bringing many major changes to Sacramento, changes for the better for late-deafened adults.

We are all winners at facing deafness. Deafness is just one part of us. We are each special and unique and each of us has it within ourselves to win!

In May of 1987 my journey into deafness began. When I was first told that I had permanently lost my hearing in one ear and that I could lose my hearing in the other ear at any time, the doctor might as well have told me my skin had permanently turned green. These things happened to other people, not to me... I did not believe him.

I had no experience with deafness to guide me. When I was growing up, my father was a football coach. He taught my sister and me many sports and how to win and lose gracefully. We had an ideal childhood spending summers swimming, playing tennis, and teaching swimming with our dad. My idols were my father, Mickey Mouse, and Doris Day. Growing up was a happy time in my life. This warm and loving environment in which I was raised greatly influenced the way I view the world.

When I lost my hearing, I had other losses at the same time. My father died... then I lost my hearing... then I was faced with discrimination on the work place for the first time in my life. My response to these changes was quite severe. I became immobilized by stress and anxiety. I could not imagine a life without hearing, after all, I could still hear out of one ear.

I never really faced the stressful things about the loss of my father; I could not face those feelings. Instead I concentrated on the things that I could change.

I had to overcome my perceptions, misconceptions, and prejudices about deafness. I had to learn to cope with my feelings about myself, my identity, the possibility of being disabled, handicapped, different. It was quite a challenge since my whole world had been turned upside down. Learning to cope with being hard of hearing was the least of the challenges.
The change in my status at work was the crisis that changed my identity. I had been a manager of a ten-person team. As art director I provided direction for all art projects for our state department. When I requested accommodation for my hearing impairment, I was faced with an organization change that forced me to report to a co-worker and took away my managerial responsibilities. This above all of the other problems was the most difficult for me to cope with. I fought this because I felt that it was something I could change. I thought the laws protected me from discrimination of this sort. The law did not protect me, I was wrong.

I could change my attitude about deafness. I could prepare myself, and learn the skills I would need if I became deaf, although I did not believe that I would become deaf. I took several positive steps toward achieving these goals:

1. Created a team and a self-help group. This team consisted of Fred Lewis, Chief of the State of California Office of Deaf Access and Charlene Mac Kenzie, Training Officer for the Department of Social Services, both hearing impaired, my friends and mentors. Together we researched and delved into all aspects of hearing loss. The Office of Deaf Access has an extensive library of information about hearing loss and we help others who were interested in understanding hearing loss. We called this group HIP, the Hearing Improvement Program, and invited all people interested in hearing impairment to join us.

2. My husband Jim and I began sign language classes. I am so glad we both took these classes because we could communicate immediately when I did become deaf.

3. I took classes in speechreading. After I became deafened, we both took a class in speechreading, it helped Jim to understand how he could help me to speechread him.

4. I participated in the Disabled Advisory committee for the State of California, Department of Social Services.

In these four ways I learned about all disabilities and overcame my prejudices. I learned to accept people with disabilities as they are, as real people with personalities, hopes, and dreams of their own. I made friends through these activities. These new friendships are more enduring than any of the friendships I have made in the past because we share and care about one another.

Then, it happened. I became deaf suddenly, overnight, in May of 1990. The doctors do not know the cause of my deafness. This was frustrating. If I knew the reason, maybe my deafness would have been easier to accept; but not knowing increased my anxiety. Questions were left hanging in the air, unanswered and unanswerable. They said my hearing could return just as I had lost it. I kept waiting for it to return. This was almost worse than being able to accept the condition of deafness. Again I faced grief, stress, anxiety, and fear. I could not control these reactions and I bounced around the grief model from anger, bargaining, depression, denial, shock, and fear. The one thing I could not do was accept my deafness. Acceptance came much later. After all, my hearing could return, right?
THE GRIEF MODEL

SHOCK
at the
LOSS

ACCEPTANCE
OF REALITY
Adaptation
to reality

DENIAL
disbelief
rejection of
reality

DEPRESSION
paralysis
immobility
helplessness
overwhelmed

ANGER
Fear
Pain
Panic
Feelings

"VICTIM"
stance

BARGAINING
"God, if you'll give me back my hearing, I'll
go to church and be a good person", etc.

The Grief Model shows the different steps that a person goes through when they have sustained a loss such as deafness. These are normal steps and they do not go in a logical pattern. You can bounce around from one to the other at any time during your journey to acceptance and recovery. Often times, long after you have accepted the reality of deafness, you will find yourself battling one or many of the elements included in the grief model. This is normal. Hopefully you will learn along the way how to battle each stage successfully and get on with living.
The five star Grief/Loss Model was developed by Elizabeth Kubler-Ross and David Fontes. I have modified the original design to reflect the grief process when losing one's hearing.

Deafness! My mental reaction was worse than the reality. When I learned that I was deaf, I was immobilized by stress and anxiety. After a month of inactivity, isolation and depression I realized that if I continued the way I was going, I would be a good candidate for a mental institution. Facing life as a deafened adult was much easier than facing life in a mental hospital. I chose to face deafness and life.

To break the grief cycle, I researched, learned and used strategies in:

- **Stress Management** - Utilizing deep breathing exercises, visualizing a time and a place that brings you happiness, relaxation techniques of alternately tightening and relaxing muscles beginning at your head and work down until your entire body is relaxed.

- **Coping** - Using everything within your power, mind, and body to deal with problem situations that come up, taking positive steps to resolve the problem. Learning how much you can do, then increasing your skills and abilities one step at a time. Remember you are a beginner at deafness, do not expect too much of yourself. Do the best you can and take steps to learn skills that will assist you to continue participating in activities with your friends.

- **Communication skills** - Sign language and speechreading are a beginning to learning how to understand speech without hearing. Learning to be assertive, and teaching other people how they can help you is a big step. Communication skills includes learning to request a notetaker for important meetings and doctor appointments. If a notetaker is not available, ask the person to write.

- **Positive thinking** - The power of positive thinking has been known to help people overcome many problems and even helped people to recover from illness. You can begin each day with a positive thought by purchasing a positive thoughts calendar and reading the thought each day. Keep your mind on what you can do... and when you find yourself drifting back into self-pity, you can control your thoughts by thinking about something that makes you happy.

- **Attitude control** - Focus on your abilities. Control your attitude about small things. Take each individual event one step at a time. Laugh and smile, you will respond and so will the people around you. Control your feelings and change your attitude about deafness by educating yourself. Once you understand deafness, your attitude will improve. You will find that you will be able to teach others too. As your attitude improves, so will the attitude of your friends and loved ones.

- **Exercise and nutrition** - Keep up a normal exercise routine and remember to eat healthy meals. good nutrition and exercise can reduce stress enabling you to deal with situations calmly.

All of these areas hold the key to healthy living, overcoming stress, and returning to the mainstream of life. I have included information on these topics in my book "Deaf? Me? What's Next," which is about surviving sudden deafness.

I used my mind, body, and the interrelationships to make my own brand of magic, to overcome my response to deafness.
THE INTERRELATIONSHIPS BETWEEN MIND & BODY
A WINNING TEAM IN FACING DEAFNESS

YOU

YOUR INDIVIDUAL STRENGTH & ABILITY

FOCUS ON ABILITY

MOTIVATE YOURSELF TO PLAN, SET GOALS, TAKE ACTION!

YOU HAVE IT WITHIN YOURSELF TO CREATE MIRACLES!

USE EVERYTHING WITHIN YOUR POWER TO CHANGE NEGATIVE TO POSITIVE . . .

THROUGH

YOUR

YOUR MIND IS YOUR BEST ASSET.

"MIND OVER MATTER" MIRACLES AND MAGIC ARE PERFORMED BY YOUR MIND!

BELIEVE!

&

BODY

YOUR BODY RESPONDS TO:
- GOOD NUTRITION
- EXERCISE
- & YOUR MIND

YOUR MIND & BODY RESPOND TO:
- SPIRITUAL & EMOTIONAL UPLIFT

THINK POSITIVE!

INTER-RELATIONSHIPS

RELATIONSHIPS:

YOUR MIND CONTROLS & YOUR BODY REACTS

THERE IS MAGIC WITHIN EACH ONE OF US . . . IT BEGINS IN OUR MINDS . . .

YOUR MIND HOLDS THE KEY . . . TO YOUR FUTURE

GOOD MENTAL HEALTH IS ATTITUDE FAITH & HOPE IN THE FUTURE.

THERE IS LIFE AFTER DEAFNESS
In the mind and body chart, I have shown the basic relationships as I see them between your mind and body. I believe that you and your individual strength and ability will make a difference in how you relate to the world around you and cope with deafness. You can motivate yourself to plan, set goals, take action. You have it within yourself to create miracles.

Use everything within your power to change negative to positive, if you look at the chart, you will see how everything flows from your mind. Your mind is your best asset. If you truly believe you can do something, you can. You may think, "but I can't hear!". This is true, in the traditional sense, you cannot hear. But you can obtain skills that provide you with a sense of hearing and understanding. When I am relaxed and chatting with a friend, I often forget that I cannot hear. I become so relaxed that I feel I am hearing and actually hear their voice as they talk, within my mind. You can overcome self-imposed obstacles and limitations.

Following through the chart, the chart shows that your body responds to good nutrition and exercise. Both your mind and body respond to spiritual and emotional uplift. If you think positively, you will feel better in mind and body. One thing that I found helpful was to use a positive-thoughts calendar. I begin every day with a positive thought.

The final thought on the chart is that your mind controls and your body reacts. These are interrelationships between mind and body. Good mental health is a positive attitude, faith, and hope. There is magic within each one of us. Our mind holds the key to our future and our happiness. We control our minds and we control our future.

You can turn unexpected change into personal success by creating and following a plan... your plan for success and happiness! To face deafness, take positive actions, one step at a time, or if you are impatient like me, take many steps at a time.

Beyond researching stress management, coping, brainstorming communication skills, using positive thinking, working with attitude control, making an attempt to eat right, and getting proper exercise, I took the following actions:

- I wrote and illustrated projects about late-deafness for public awareness which helped to change my attitude, perceptions and fears. I learned about deafness. I removed my fears through understanding.

- I wrote and illustrated books, pamphlets, positive-thoughts calendars, placemats with lipreading basics, and many other projects that can help others survive deafness, and in doing so, I provided myself with a directions for the future. My goal is to help others like me who faced sudden deafness alone. Neither doctors, service agencies, nor health care professionals were equipped to deal with the emotional effects of deafness.

- I use the power of positive thinking to give me hope and faith in the future.

- I have learned to give and receive love again. I have learned to love myself the way I am and with this love came the awareness of happiness. I have learned to live, love, and laugh again. I was forced to look closely at myself and make changes I would never have thought of had I not been faced with deafness, changes for the better.
In May of 1991, our service agency provided a coping-skills class for late-deafened adults. Through this class a nucleus for an ALDA group was formed. ALDA has provided me with something that no other self-help group could provide. In our small group in Sacramento, we share compassion for one another. Let me share this prescription written by Steffanie Dravis with you, so you too can help.

A prescription that can be given immediately, quickly and with lasting effects.

**Compassion:** Compassion is perhaps the most important gift any professional or family member can give to a newly deafened person. Compassion. Not sympathy, pity, or even empathy. Compassion, the ability to see the deafened adult as a whole person, to look them in the eye with acceptance, to communicate, even if only briefly, I see you, not the label, "deaf", handicapped, or problem, but you as a person, full of feelings, questions, ideas, fears, needs, and desires. You are still you, a person, whole, even without all of the physical parts of you functioning. I don't have all the answers, I can't solve all of your problems or take away your fears and pain, but you are still your own unique person. You'll make it. You still count in this world'.

Two minutes of compassion can provide a late-deafened adult with the strength to carry on and to face deafness and life with renewed hope for the future. Deafness is an ongoing stressor. Our perceptions and feelings about deafness and ourselves are the keys to recovery. Deafness is just a fact of life, not a roadblock to living. By using these strategies, I am now coping, living, loving and laughing! I won!
PSYCHOSOCIAL REHABILITATION OF LATE-DEAFENED ADULTS

Curtis W. Inoue

Curtis Inoue, M.A., is a native of Honolulu, Hawaii. He was deafened by neurofibromatosis, type 2 (NF-2) in 1983, four years after obtaining his B.A. in Psychology. He studied sign language as well as business and computer science at National Technical Institute for the Deaf (NTID). During 1990, he was president of Deafness Education and Awareness through Friendship (DEAF) club at NYU. He received his M.A. degree in May 1990, and presently works as a vocational evaluator at the Lexington Center in Jackson Heights, New York.

DEFINITION OF TERMS

Before proceeding any further, a need to define the terms used in the title of this paper is in order.

The term psychosocial is used to emphasize that the difficulty faced by late-deafened adults not only involves their own psychological adjustment to their hearing losses, but also the societal demands and social forces that they encounter in everyday life.

The term psychosocial rehabilitation is used to distinguish it from vocational rehabilitation, which is the process whereby people with disabilities are helped to become productive and employed members of society. In fact, it is my opinion that with any acquired communication disorder—such as hearing impairment—it is important to think first of psychosocial rehabilitation.

Late-deafened adult is used here to refer not just to elderly deafened individuals but to all those who acquire their deafness in the post-adolescent period, whether in young adulthood, middle age, or old age. The reason that I chose to define this period this way is because, according to Erik Erikson, it is during adolescence that we develop an identity, a sense of who we are. So the premise or assumption here is that late-deafened adults, before losing their hearing, have had their identities, including their identities as hearing people, well-formed.

INTRODUCTION

It is my opinion that late-deafened adults are an underserved population when it comes to social and rehabilitative services. There are two reasons why I say this.
First of all, based on statistics by Schein and Delk (1974), Luey (1980) noted that "78% of all deaf people in the United States lost their hearing after having reached adulthood" (p. 253). In other words, the vast majority of deaf people are late-deafened adults. Then, too, most social and rehabilitative services for the deaf are directed toward the congenitally deaf and early-deafened populations. Thus, by considering these two facts together, it can clearly be seen that late-deafened adults are indeed an under-served population. According to Kyle (1987), "Perhaps the greatest priority in hearing loss is service provision and in most countries this has hardly begun to meet the needs of those who acquire a loss" (p. 201).

However, late-deafened adults may not be entirely inculpable for this lack of services, for Stone (1987) has suggested that it is the stigma of being deaf that has "hampered research, delayed systematic study of the problem, prolonged ignorance among hearing people and, most importantly, it has inhibited those with a hearing impairment from seeking help" (p. 114-115). But this, needless to say, does not lessen the need for services.

**PROBLEMS**

Over the past few years I have learned that there is a vast ignorance on the part of many people, including professionals, about acquired hearing loss and its psychosocial implications. Indeed, if one were to search the professional literature, he or she would find a dearth of research on adventitious deafness compared to the plethora of material that exists on congenital and prelingual deafness. Furthermore, what studies do exist were not very well done. Many were done with samples that were biased—e.g., "too old, too male-dominated, too professionally biased, include prelingually-deaf people, or are drawn from clinical referrals" (Jones, Kyle, and Wood, 1987, p. 28)—and, thus, may not be representative of the late-deafened adult population. It is this lack of a knowledge base that undoubtedly accounts for the gaps in the design and delivery of services.

But surely some services do exist for the deafened adult population? There is no denying that. However, what services do exist are primarily of a medical and technical nature, such as those that provide hearing aids and assistive listening devices, lipreading training, hearing therapy, etc. As a result, "Rehabilitation has implied provision for the individual alone making adjustment their sole responsibility. Inevitably this leads to a sense of isolation and our services beyond hearing aid issue have tended to focus on this problem" (Kyle, 1987, p. 201).

Of course, I am not at all denigrating those who provide medical and technical services. Needless to say, these do have a place in rehabilitation. However, too often medical and technical professionals tend to forget the human side of the equation. For example, a late-deafened adult may be initially resistant to the fitting and use of hearing aids, to speechreading training, to learning sign language, etc. The individual will not overcome his or her resistance unless and until he or she gets past the denial and bargaining stages of the grief process. Medical and technical professionals often fail to recognize or, at least, affirm this. In other words,

Most scientific attention to hearing impairment has been focused on its interference with communication, even though it disturbs more than that. Indeed its noncommunication aspects also contribute heavily to its emotional impact. What is critical here is an approach that recognizes that hearing impairment has both intellectual and emotional components. (Stone, 1987, p. 114)
What Stone is saying is that adjustment to hearing loss is fundamentally a psychological process. Therefore, "a definition of need, roles and responsibility is called for which involves co-ordination and co-operation of medical, technical, psychiatric, psychological educational and social work fields to develop a comprehensive service with channels of appropriate help not only available but invitingly obvious" (Rimmer, 1977, p. 79).

Why are late-deafened adults in need of psychosocial rehabilitation? According to Brook-Hughes (1977),

The social consequences of severe hearing impairment when it occurs in adult life cannot be so generally interpreted as in the case of children, since it has not affected the normal development of the individual. It can nevertheless have a very traumatic effect upon the personality, calling for a period of adjustment which must inevitably be painful, particularly if the hearing loss has been of sudden onset. Gradual deterioration of hearing, too, can be equally difficult if the individual is unable to accept it.

Furthermore, Knapp (1948) showed that the most affected areas lay in relationships, the most significant feeling is loneliness, the singular fear is to be thought stupid, and the height of anxiety is the insecurity of social situations. Then, of course,

Human beings have strong social needs. So it is not surprising that the hearing handicap, since it is a social disturbance, has strong effects on the persons suffer from psychosomatic illnesses and inconveniences than normally hearing or even born deaf people do. The marginal social position the hard-of-hearing or deafened person is pushed into deranges his/her self-confidence (Claussen and Schuck, 1987, p. 112).

What specific psychosocial concerns are late-deafened adults in need of help with? Meadow-Olans (1985, p. 41, 42) noted that

Many clinicians agree that depression and withdrawal with resultant isolation are the most prevalent psychological responses to severe hearing loss... Research findings support these observations, as do reports from individuals who have experienced hearing loss.

Reports of nervousness, anxiety, and heightened fearfulness, and irritability are common in accounts of deafened persons, professionals who work with them, and hearing persons with simulated deafness. Embarrassment is also frequently reported.

The breakdown in communication is known to be a universal stressor, and this stress can probably produce adverse perceptions such as rejection. For the late-deafened adult socializing then gradually shuts down.

Late-deafened adults suffer fatigue caused by the effort and energy required to try to hear or speechread and, if they are totally deaf, to make themselves understood. This fatigue reduces their physical and emotional capability to function and to cope. Thus, it is not surprising that "one typical reaction to hearing loss is a pervasive feeling of helplessness" (Harvey, 1989, p.112). And to Kyle, et al. (1985), "the onset of hearing loss disturbs the control that the individual can exert" (p.122). Schlesinger (1985) defined lack of control or powerlessness as "an individual's self-perception as not having the cognitive competence, psychological skills, instrumental resources, and support systems needed to influence his or her environment successfully" (p. 105).
While social withdrawal and isolation are one side of a coin common to those with acquired hearing loss, the other side of that coin is dependency. Often, a deafened adult will feel torn between the fear of isolation and the fear of dependency. This too can cause stress.

From the discussion above it would be easy to conclude that becoming deaf results in people becoming "neurotic." However, it is important to note that the anxiety, insecurity, depression, etc. that are experienced by deafened adults are responses, not symptoms. They are to be seen in relation to the social environment and cannot be divorced from it.

There are several factors that, in my opinion, may influence the adjustment or maladjustment of deafened adults to their hearing loss. These are:

1) Stigma. Those who feel stigmatized by their deafness will not adjust as well to it as those who do not feel stigmatized. They will not be willing to learn sign language nor to disclose their deafness to others but will instead attempt to pass as a hearing person. They would rather be thought stupid or snobbish than deaf. This, of course, is much too simplistic because the "perception that stigma exists ... can only arise as the result of experiences gained through the process of interacting with others, at home, with the family, socially, and vocationally" (Jones, Kyle, & Wood, 1987, p. 15).

2) Pre-morbid perception of Deaf people. If, before losing his or her hearing, a deafened adult perceived Deaf people as deviant and inferior, then he or she probably views himself or herself as deviant and inferior. That is to say, we are indeed our belief systems.

3) Cognitive style. This refers to the preferred mode of taking in information. Becoming deaf has, it seems, a greater impact on those who are (or were) aurally oriented than it does on those who are (or were) more visually or tactilely oriented. In other words, the adjustment from having to receive information via a verbal-aural mode to receiving it via a visual-gestural mode (i.e., speechreading and/or sign language) is a tremendous one that aurally oriented people have to make. This may account for the fact that many deafened adults have problems processing information. As a personal example, I can remember, as a graduate student sitting in class or even now during staff meetings at work, how I would watch the interpreter and be pretty much able to follow along with what was happening. However, when it came to actively participating in what was happening—discussions, asking and responding to questions, etc.—I found it difficult to do. It seemed as if the information I received was not being easily processed by my mind, perhaps because there was that one extra step—namely changing the signs to words before they could have any meaning—that was required. Needless to say, this is all speculation. Nevertheless, research should be undertaken into this area of how acquired hearing loss affects learning and cognition.

These are just three of perhaps many factors that I believe may influence a late-deafened adult's adjustment.

As for the social effects of later deafness, "theorizing social scientists, clinicians, and deafened individuals agree that the redefinition of self is a dramatic necessity and that many hearing-impaired persons have a sense of 'marginality' for years" (Meadow-Orlans, 1985, p. 43-44). This is perhaps the most significant issue facing the late-deafened adult, the need to resolve this marginality or identity confusion.
Identity vs. Identity Confusion

An experience that seems to be common to most, if not all, late-deafened adults is that of identity confusion. Who am I, now that I can't hear? and Where do I belong, in the deaf world or in the hearing world? are questions that late-deafened adults frequently ask. Here we have people who are no longer able to function fully and effectively in the hearing world but at the same time are not (yet) able to function fully and effectively in the Deaf world. According to Erik Erikson (1980), identity confusion is characterized in part by:

1) Distantiation. [This] state consists of a painfully heightened sense of isolation; a disintegration of the sense of inner continuity and sameness; a sense of overall ashamedness; an inability to derive a sense of accomplishment from any kind of activity; a feeling that life is happening to the individual rather than being lived by his initiative; a radically shortened time perspective; and finally, a basic mistrust, which leaves it to the world, to society, and indeed to psychiatry to prove that he does exist in a psychosocial sense, i.e., can count on an invitation to become himself (p.135-136);

2) Diffusion of time perspective. The ... person may feel simultaneously very young, and in fact babylike, and old beyond rejuvenation. Protests of missed greatness and of a premature and fatal loss of useful potentials are common... Such complaints as, "I don't know," "I give up," "I quit," are by no means mere habitual statements reflecting a mild depression; they are often expressions of the kind of despair which Edward Bibring (1953) has recently discussed as a wish on the part of the ego "to let itself die" (p.136);

3) Diffusion of industry. [S]evere identity diffusion is regularly accompanied by an acute upset in the sense of workmanship, and this either in the form of an inability to concentrate on required or suggested tasks, or in a self-destructive preoccupation with some one-sided activity, e.g., excessive reading... [I]dentity diffusion is accompanied not only by an inability to concentrate, but also by an excessive awareness as well as an abhorrence of competitiveness. Although the patients in question usually are intelligent and able and have often shown themselves successful in office work, in scholastic studies, and in sports, they now lose the capacity for work, exercise, and sociability, and thus the most important vehicle of social play, and the most significant refuge from formless fantasy and vague anxiety (p. 137-139).

This is the primary way that late-deafened adults differ from congenitally deaf and early deafened people. Deafness is all that prelingually deaf people know and, therefore, is an integral part of their identities. In contrast, adults who acquire their deafness experience a loss of sensory capacity from which they had defined themselves (Glass, 1985; Ramsdell, 1978). Consequently, whereas many prelingually deaf people may view their deafness as a cultural phenomenon, late-deafened adults may view their deafness as something pathological.

There are at least two implications of this identity confusion:

1) "[I]n the social jungle of human existence there is no feeling of being alive without a sense of identity" (Erikson, 1980, p. 95).
2) This unresolved identity confusion results in the stifling of growth towards self-actualization—a problem that I will address next.

Self-Actualization and Acquired Hearing Loss: Obstacles to Growth

In presenting his theory of human motivation, Abraham Maslow formulated what he called a hierarchy of needs. This hierarchy consists of five levels of needs with physiological needs being the lowest, most basic level and progresses upward through the levels of safety, belonging and love, esteem, and finally, self-actualization.

Each level of need is generally prepotent over those above it. That is to say, the lower needs must be fulfilled before the higher needs emerge, dominate, and organize the individual.

As I had alluded to earlier, late-deafened adults may be confronted by an identity crisis, and this crisis or confusion, if unresolved, can result in the stifling of growth toward self-actualization. It should be clear by now why this is so.

Maslow approaches psychological growth in terms of the successive fulfillment of higher and more satisfying needs. The pursuit of self-actualization cannot begin until the individual is free of the domination of the lower needs [such as the need for belongingness]. According to Maslow, early frustration of a need may fixate the individual at that level of functioning (Fadiman and Frager, 1976, p. 341).

Am I alone in this belief about acquired deafness, identity confusion, and the stifling of growth? Consider the quotations by the following individuals:

Mary Johnstone: Because I am a hearing person who became deaf, I do not fit the norms in either the deaf or hearing cultures. In this sense, I am one of the more than 16,000,000 deafened or hard-of-hearing people who are separated from their hearing culture, yet who have life experiences that relate them to the deaf community. I can be identified demographically as deaf, but my reality of what it means to be deaf is personal and seems to elude definition.

Holly Elliot: The term Deaf has cultural connotations that have little to do with degree of hearing loss. The problem with the adventitiously deaf person is that often he [or she] does not fit into either the deaf community or hearing community. I have something of an identity problem myself. Hearing people think I’m hearing because my speech is good, and deaf people think I’m hearing because my signs are bad!

Helen Sloss Lucy: Deafened people have an acquired hearing loss. For many years of their lives, possibly for most of their lives, they have had normal or nearly normal hearing. Their language, their identities, and their social functioning are those of hearing people. In this vitally important respect, deafened people are different from people who have been born deaf, or who became deaf in infancy and early childhood. [Another] crucial aspect ... is that deafened people are in an audiological sense, deaf. Considering this, ... it is easy to understand why deafened people suffer from confusion about who they are and where they belong. They are caught between worlds.
Notice in the above quotations how closely tied identity is with group membership* (i.e., belonging in Maslow's terms). Why is this so? Psychologist Gordon Allport has observed that "it is the ground of the social group that gives to the individual his figured character. Just as the bed of a stream shapes the direction and tempo of the flow of the water, so does the group determine the current of the individual's life" (in Lewin, 1948, p. vii-viii).

So what then can be done to resolve this identity confusion, and thus, release deafened adults to grow and develop personally? One writer (Glickman, 1986, p. 9) suggested that the means of resolving marginality must be by exploring deafness, to some degree and for some time, on both a personal and a social level. This is easier said than done. First of all, there is the misconception that audiological status alone will get deafened adults entry into the Deaf community. Not so. It also takes an attitude, a willingness to subscribe to the norms and values of Deaf culture. Furthermore, Deaf culture cannot be learned solely through books, lectures, videotapes, etc. Interaction with Deaf people is, at the very least, what is required. However, non-Deaf (e.g., late-deafened, hard-of-hearing, hearing) people "do not have access to the knowledge, beliefs, and practices that make up the culture of Deaf people" (Padden & Humphries, 1988, p. 2). Access is denied them because of the suspicion that Deaf people have of the non-Deaf.

This, of course, may all be superfluous. With the advent of an organization like the Association of Late-Deafened Adults (ALDA), deafened adults now have a group they can truly feel a part of. With ALDA, things no longer have to be either/or, black and white for late-deafened adults, either they belong in the deaf world or in the hearing world. There is now that middle ground that stands between or, perhaps, transcends both the deaf and hearing worlds. As mentioned previously, identity is closely tied with group membership. The logical conclusion is that because of the feeling of belonging that ALDA gives to them, late-deafened adults are better able to claim their identity. They are no longer hearing. They are not Deaf. They are DEAFENED and can maybe even proud of it.

**Differential Effects**

Thus far, I have been discussing acquired deafness as if its effects were the same for all late-deafened adults. This, of course, is not true. Schlesinger (1985) noted that the way in which an individual reacts is related more to the meaning that the disability has for him or her rather than to the nature of it. For example, "coping with a major life crisis, such as acquired hearing loss, frequently includes revising one's view of how life is and/or should be. One meaning of the traumatic loss may be that life is not fair" (Harvey, 1989, p. 109).

Harvey (1989) also pointed out that "Becoming deaf or significantly hearing impaired at the age of 30 is phenomenologically distinct from becoming deaf or hearing impaired at the age of 70..." (p.109). He quoted Humphrey, Gilhoma-Herbst, and Faurqi (1981, cited in Meadow-Orlans, 1985) as stating that a person's "attitudes to a disorder first suffered at a stage in life when it was felt to be untimely and exceptional are different from the response to the same disorder encountered at a stage where it is conventionally expected as part of a 'normal running down'" (p. 29).

* This concept will be discussed further in the Appendix.
REHABILITATION OF LATE-DEAFENED ADULTS

How then should rehabilitation professionals approach their work with late-deafened adults? Thomas (1987) says that "Anyone involved in rehabilitation cannot do very much unless he or she becomes fully acquainted with the day-to-day problems encountered by each individual and preferably those with whom the [hearing] impaired person comes into contact" (p. 198).

Note that Thomas said "day-to-day problems." This is an important point. Wood (1987) believes that the most appropriate theoretical framework for looking at these day-to-day problems is existentialism because

The essence of the existentialist system lies in its rejection of reductionisms or determinisms in understanding the complexities of human behaviour, whether these be biological, economic, or environmental. Each quest for authenticity is therefore specific and personal rather than general. When we see the immensely complex life situations of the deafened such an approach has an obvious appeal (p. 216).

Thomas, in his statement quoted above, also said that acquaintance should be made with those "whom the [hearing] impaired person comes into contact," and rightly so, because for successful adjustment to occur there must be involvement of support structures such as the family, friends, peers, professionals, etc. (see Lowensteyn-Koopman, 1987, for an excellent discussion about professionals and hearing loss). Claussen and Schuck (1987) explain:

The affected person's habitual forms of communication, as well as those of his relatives and friends, become ineffective or useless. A new organisation of the forms of interaction in the person-environment-systems of the hearing-impaired person becomes necessary. Every person-environment-system is in a status of inner balance or struggles to maintain it. This inner balance is disturbed by the hearing impairment and it is only by processes of reciprocal adaptation that a new balance can be achieved. In this way, emotional and social isolation can be avoided and, for example, suicide be prevented (p. 216).

Along this line, a program such as the Breakthrough Trust organization in Birmingham, England would be ideal for a deafened adult's situation because its aim is to integrate deaf and hearing people through aiding not only the deaf but the hearing as well. They recognize that deaf(ened) people should not have to bear the full responsibility (or burden) in making communication with hearing people happen. Hearing people also share that responsibility.

One final point, the astute reader should have noted that there is a unique dilemma that the deafened adult is confronted with in seeking rehabilitation services.

The deafened have the drawback that this handicap by its very nature, deprives them of the facility seriously handicapped people need most to speak about their problems with those they will ask for help in the first place: spouse, children, other relatives, neighbors, doctors, social workers. Oh to be sure they are capable of speaking, but I mean speaking while asking for an answer, and this answer they cannot hear, and all this precisely in the beginning of their life as deafened, when they most need help, consolation and comfort (Lowensteyn-Koopman, 1987, p. 255).
In other words, while it may be easy for a late-deafened adult to ask for help, it is not easy to "receive" it. Of course, one possible solution is to write down or type things up for the late-deafened individual. However, it is suggested that hearing people do not wait for the individual to ask that this be done for them. Because of what is called courtesy stigma, many late-deafened individuals feel that it is a burden for the other person to write things down for them whether this is true or not and thus, will not ask.

To sum up what has been said thus far, "the individual person's psychological make-up, life style, family, work, and social life are at least as important as technical knowledge in gaining a better understanding of the process of adjustment and in the design of rehabilitation programmes" (Thomas, p. 1987, p. 196).

CONCLUSION

Hearing loss acquired in adulthood brings along radical changes in daily life. Every aspect of life is affected, and this is a great emotional strain. Changes in the social situation, in the family, among friends and in the social world. These are painful changes that we may never get used to—even though we try to adjust. Adjustment is a long-lasting and painful process for the individual who has lost his/her hearing. This process receives minimal attention in the existing rehabilitation programmes (Kaulum, 1987, p. 227).

However, as I hope I have made clear in this paper, this process is one that requires and deserves attention. Rehabilitation programs will come about only with further research and the recognition that medical and technical services alone are not sufficient in helping an individual adjust and with deafened people themselves coming out of the cracks, banding together, and demanding their rightful need for services. And once these services are established they should be comprehensive and adapted to meet the needs of the individual.

Kaulum (1987) put it best:

the main aim is to make the deafened people as self-sufficient as possible, enabling both the deafened and those around them to live with the hearing loss, not merely survive. This is a long process and we are totally dependent upon help from others. Our whole lifestyle has to be changed, and this we do not want. We need assistance, sympathy, time to change our expectations of ourselves and the environment. It is important to remember that the people in our environment also are in need of help. Let us hope for better times! (p. 230).
APPENDIX

In order for the reader to understand why it is so difficult for many late-deafened adults to satisfy their belonging needs (i.e., why there is a crisis of identity), it is important for him or her to understand the dynamics of group membership as related to what is called the Deaf community. To do this, I will use excerpts from B. M. Schowe’s excellent monograph entitled, *Identity Crisis in Deafness*.

The deaf aggregate and the social entity of the deaf, which we imprecisely call "the deaf," are quite different populations. The deaf aggregate includes all who are classified as "profoundly deaf" when tested on audiometric devices. They could be called the "audiometric deaf." But those who compose the coherent social entity of the deaf cannot be so readily identified. Some may not even be profoundly deaf so far as decibel loss is concerned (p. 42).

What distinguishes between a group (or coherent social entity) and an aggregate is the interdependence of individual members. The group has it, the aggregate does not. This interdependence is not mere gregariousness. It is interaction with others based on common norms, values and experiences (p. 42).

[The] deafened are ill-equipped to shift their lifestyle, their norms and values, to those of the deaf in-group or we-group or, more explicitly descriptive, coherent social entity of the deaf. Among the latter, it is customary to do some categorizing of their own. They commonly refer to the...deafened as hard-of-hearing, regardless of their audiometric status. Although many with excellent credentials and life-long membership in the deaf in-group have sufficient residual hearing to classify as hard-of-hearing on the audiometric tables, they are accepted without question if they subscribe to norms and values of the group and give evidence of nominal loyalty (p. 43).

No doubt the...deafened would be welcomed to the group on similar terms. One trouble is that many of these deafened are peculiarly sensitive to the stigma which attaches to the sign language of the deaf. Another one is that they cannot readily shift from the friendships they have accumulated over their hearing years to the milieu of a different set (p. 43).

Thus lies the dilemma of late-deafened adults.

REFERENCES


THE EXPERIENCE OF LOSS AND GRIEF AMONG LATE DEAFENED PEOPLE: A REPORT OF RESEARCH AND THEORY

Frank R. Zieziula
Katharine Meadows

Frank Zieziula, Ph. D., C.P.C., is a professor of counseling in the Department of Counseling at Gallaudet University and a certified professional counselor in the State of Maryland. Dr. Zieziula has spent over 20 years providing services to and teaching professionals about deaf and hard-of-hearing people. For the past five years, Dr. Zieziula has focused professionally on grief and bereavement theory.

Katherine Meadows, M.A., has worked in counseling services at Whitman-Walker Clinic, AIDS Services of Washington, D.C. and Deaf Reach of Washington, D.C. Her M.A. degree is in mental health counseling from Gallaudet University.

Our goal today is to make an attempt through research and theory to help you understand how you may feel being a late deafened person and what you need to accomplish in your life from a psychological perspective to be at peace with yourself and to succeed in your current career and social environments. This is truly a monumental task. If we touch the surface of this goal, we will be fortunate.

Our presentation is meant for a specific consumer audience, that is, people who are themselves late deafened. Yet we would hope that the content of the presentation will touch the lives of people who are hard of hearing and people who have been born deaf. In addition, we believe the research, which will reported on during this presentation as well as the model for successful adaptation to loss, which we will propose, can assist a variety of professionals who have as one of their primary responsibilities, the goal of assisting late deafened people to achieve successful psychological, social and career happiness.

The first part of our presentation will focus on a research study of a sample of late deafened adults within the United States, specifically people within the Washington, D.C. area. The study was conducted at Gallaudet University by Ms. Katharine Meadows, a mental health counselor for deaf people. The remainder of the presentation will offer a theoretical model for coping with the event of becoming late deafened. We feel this model is practical in assisting both the person who is deafened understand the psychological events following
the loss of her/his hearing and the professional who must assist the late deafened person adapt to the circumstances of his or her life.

First, although statistics show that the predominant group (78%) of deaf people have become so after language development, the preponderance of psychological research on deaf people has focused on prelingual deaf people, that is, people who have become deaf before language development. The specific research studies on the psychosocial nature of late deafened people in the United States in this century are identified in appendix one. As you can see, the list of available research studies is short.

When researchers have studied late deafened people, most have done so from a "mental disorders" perspective. The researchers have assumed that people who become deaf after the development of language were prone to personality adjustment problems and/or mental disorders. Specifically, many of the research studies focused on psychologically disturbed people who had hearing impairments and then attempted to explain the current mental illness by way of the event of the loss of hearing. The assumption was that the loss of hearing was the causative factor of the mental disorder.

Although these research studies provide relevant information to consumers and practitioners, most past research studies are limited in furthering our understanding of normal development, that is, the normal psychosocial adaption following the loss of one's ability to hear. The current study conducted at Gallaudet University approached late deafened people from a "wellness" model. The study assumed that deafness occurring within an individual's life span would be a serious loss that would result in a healthy adaptation to loss by the person and not necessarily a psychopathological adaptation to the loss. The adaptability to the loss of hearing is assumed to be normal life process that is similar to the process of "grieving" experienced by an individual who has lost a loved one through death. Interestingly, a decade ago people believed the lengthy grieving process due to a death loss was also most likely pathological. Now we realize adaptability to death loss is much longer than previously expected and the grieving process is much more complicated that first explained, yet normal in its unfolding. Therefore, the purpose of our research study was to find out through interviews how late deafened people grieved after finding out that they had become deaf and how they adapted (psychosocially) to their loss. What was unique about the research methodology of this study is that the researchers simply, but effectively, sat for hours and talked with late deafened people about their experiences. What they told us, directly, in their own words rather than psychological instruments was worth our time in listening.

One purpose of this research project was to develop a model, a theory of understanding the grieving process of late deafened people. The only model to date, which has been applied to late deafened people is the model of grieving presented by Elizabeth Kubler-Ross used to explain people's psychological adaptiveness to the event of dying. The stages in Kubler-Ross's model are: 1. denial 2. anger 3. bargaining 4. depression and 5. acceptance. Kubler-Ross's model of "Stages of Grieving" is limited in its ability to explain the experience of becoming deaf for a late deafened people and more limited by social service personnel who hope to help late deafened people. The concept of stages of grieving connotes an orderly process of adaptability that has not been proven by research. Second, Kubler-Ross's model deals primarily with the emotional reaction to the event (in her case dying, in our situation, loss of hearing). This is important but limited when trying to understand the overall life of a late-deafened person. Therefore, we will present a new model that we hope will build upon the theory presented by Kubler-Ross yet one we hope explains an individual's adaptation through a task oriented approach to adjustment.
Our current research involved 11 participants, seven women and four men, all Caucasian, ranging in age from 18 to 66. The age of onset of deafness ranged from nine to 58 years. In almost half of the cases, the cause of deafness was unknown. Others reported the cause of deafness to be surgery, visual infection, brain tumor or traumatic head injury. Eight participants lost their hearing in less than one month, with five of them lost their hearing in a 12 hour period of time. The remaining participants lost their hearing in less than six months. Three of the participants used American Sign Language to communicate, three used simultaneous communication using pidgin signed English, three relied on speech reading supported by pidgin signed English and two relied solely on speech reading.

Through a process of lengthy multiple interviews with each of these late deafened people, we were able to decipher five major adjustment themes from the stories of the lives of each of these people: spectrum of emotional responses, secondary losses, confusion of identity, acceptance, and need for competent professional assistance.

The first theme is that of *a spectrum of emotional responses*. Participants identified experiencing an assortment of personal feelings after having become deaf, specifically, disbelief, shock, anger, hopelessness, depression, anxiety, fear, guilt, awkwardness, acceptance, boredom, and hope. Participants described a complex array of mood changes that frequently involved one, two, or multiple emotions depending on the new life situation they faced. These experiences of assorted moods did not end after a few months or in some cases even years. These expressions of emotions were not consistent or orderly. The mood swings and emotions existed and were inhibiting in adapting to tasks of daily living.

The second theme identified by the participants was that of adaptation to their *secondary losses*. In addition to the obvious loss of one's ability to hear, participants identified other losses in their lives that were related to their loss of hearing, distinct from it, yet at times, just as powerful. The just as powerful issue was very important for many of the participants. Secondary losses hurt badly, equal to, and in some cases more than the physical loss of hearing itself. Common foci emerging in this category were the loss of significant relationships with friends, lovers, families and colleagues, and the loss of social activities, the loss of work and school activities, and the loss of environmental cues.

The third prevalent theme was that of *confusion of identity*. This theme included concerns of identity as a "deaf" person or identity as a "hearing" person and identity independent of hearing status. The issue of communication modality was evident in this theme. Initially communication was linked solely to survival. As time passed, communication became linked more to an identity of self in relation to the deaf or hearing worlds.

The fourth theme was that of *acceptance*. This theme was two-fold, a concern over acceptance of the permanence of deafness and acceptance of self by others. In general, participants accepted their physical hearing loss, their "deafness" within the first two years following the hearing loss. Although all the participants eventually reached a point when they could acknowledge their deafness, many expressed a greater concern because significant others had problems accepting their physical and social conditions. Participants who had become deaf as children reported that it had taken their parents especially their mothers, much longer to accept the fact of their deafness. Some participants stated that their parents have never accepted their disabilities.
The final theme identified by the participants was the need for competent professional assistance. Participants frequently expressed a need to have their hearing impairment and the resulting life changes understood by professionals such as medical and social support personnel. The participants felt that the professionals with whom they made contact did not fully understand their situation and could not offer appropriate, specific help especially related to activities of daily living. There was a real sense among the participants that professionals were really not listening and, worse, were not really understanding their life situations.

In summary, this pilot study presented us with some important information about the psychosocial processes people experience when they encounter a severe hearing loss. More importantly, late deafened people are telling us that what happens to them when they become deaf is more than a physical condition of lack of hearing and more than a problem of communication. The ramifications of a hearing loss on the psychosocial world of the people affected is profound. Yet, the participants are telling us, in their own way, that the process of coming to terms with their multiple losses is not inherently or automatically pathological. Although specific life events and specific intense feelings, in isolation, would lead us to conclusions supporting susceptibility to mental disorders, the process is more complex and more normal than originally understood.

From this study, let us bridge the presentation to an adaptability model that we hope will be helpful to people experiencing late deafness and professionals who will work with late deafened people. The adaptability model is credited to J.W. Worden (1991) who works with people who are experiencing a loss due to death. Yet, from what we learned through our pilot study this model is applicable to people who have become late deafened. Further research will determine the fit of this model to the lives of late deafened people.

The model assumes that when an individual loses her or his hearing she or he has suffered a significant loss and that there are specific psychological tasks that must be accomplished to deal with the loss. The following are the four tasks of adaptation to the loss of hearing for a late deafened person: accept the reality of the loss, work through the pain of the loss, adjust to the environment and emotionally reinvest one's life in relation to the loss. One task is no more important than the other and unlike the stage development theory of Kubler-Ross, it is not assumed that one task must be accomplished before moving on to the next. Each task is a concern of the individual throughout her or his life, with some tasks taking priority at certain points of an individual's life. This is consistent with the research results found in the Gallaudet study.

The first task of adaptation is that of accepting the reality of the loss. This task focuses on coming to terms with the fact that an individual's hearing loss is irreversible and that changes in one's life must therefore result. This task was consistently evident in the Gallaudet research. Most important, it was a task that was never fully accomplished by the participants in our study. New situations, new environments, new social relations present new dilemmas for people coming to terms with their deafness.

The second task is that of working through the pain of the loss. A person must be able to express the emotions she or he felt about the experience of the loss. An individual must be able to feel the experience and communicate these feelings as well as understanding the experience intellectually. This was most evident in the Gallaudet research in the presentation of the theme of "spectrum of emotions." The feeling of being on an emotional roller-coaster is consistent in the lives of all the participants and apparently necessary to make the adjustment to new ways of living.
The third task is that of **adjusting and adapting to the environment (work and play)**. The individual must adjust all aspects of her or his life to the confines of the hearing loss. The person must come to terms with the loss and in many cases, develop new career, personal and social goals. Communication is a very important part of this task. The apparently never-ending dilemmas of this tasks point again to the nature of this model; these tasks remain during the individual's entire life. They are not accomplished in an identifiable period of time. Biological, environmental, career and family changes can bring any task to the forefront of psychological concern.

The last task is that of emotionally re-investing one's life in relation to the loss. With this task, an individual comes to some existential understanding of the loss and uses the understanding as a means to make sense out of her or his life and the world. Those of you who have learned from your loss and have directed what you have learned to a career in service of other people who are deafened understand the concept of "re-investment" that this task addresses.

Although the tasks are common for all people who are late deafened, the nature of how they are achieved, the quality of success and time of accomplishment will be individualistic depending on a number of factors. The five factors that will influence accomplishment of the four task of adaptation to loss for a late deafened person are actual loss/physiological state of the person, the cognitive ability and style of the person, the emotional temperament of the person, the social circumstances of the person, and the support system of the person.

The first factor is the actual loss/physiological state of the person, that is the age at which the loss occurred and degree of the loss. As our sample showed, loss occurring at different developmental stages in the lives of the people and families resulted in different reactions to the loss.

The second factor is the cognitive ability and style of the person. A creative person, a mechanical person, a flexible person, a rigid person, an intellectually diverse person and a practical person, all appear to experience the task accomplishments in qualitatively different ways.

The third factor is the emotional temperament of the person. One's ability to deal effectively or destructively with profound and varied feelings experienced during one's life after experiencing a loss will determine effectiveness of accomplishing each task.

The fourth factor is the social circumstances of the person. This factor addresses how social status and economic independence affect an individual's ability to adapt to a hearing loss.

The fifth factor is the support system of the person. This factor concerns the immediacy, helpfulness, or helplessness of the nuclear and extended families and their adaptations to the individual's loss.

Our sample taught us a great deal about late deafened people. The following points summarize what we learned: 1) We need to continue to conduct research in a manner that allows us to listen to people who have experienced this condition without pre-set biases on what we expect to find; 2) late deafened people have experienced a significant loss that must be dealt with beyond the boundaries of medicine, audiology and communication; 3)
the experiences of late deafened people are not psychologically pathological. Human beings adapt to loss, each in her or his own way.

APPENDIX 1

RESEARCH AND CLINICAL STUDIES OF PSYCHOSOCIAL ASPECTS OF LATE-DEAFENED PEOPLE

<table>
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<tr>
<th>Year</th>
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Zieziula, Meadows
Section Three:

Personal Experiences
The Diversity of Success: 
A Personal Perspective

Lee Perish  
Mary Skyer  
Sue Hajiani  
Everett Chard

Lee Perish is the current President of ALDA/Minnesota informal chapter. She holds a B.A. in sociology/anthropology and recently accepted a position as peer counselor at the Metropolitan Center for Independent Living. Ms. Perish has been very involved in a number of volunteer organizations. She was hard of hearing for approximately 15 years before becoming totally deaf in 1985.

Sue Hajiani was hard of hearing as a child and later became deaf. She wanted to be a journalist and, after working in Iran, joined Honeywell as a technical writer and has become a senior technical editor. Sue is active in volunteer groups like ALDA and Northern Sign Theater.

Mary Skyer became deaf from Neurofibromatosis (NF-2). She lives in San Francisco and works as a counselor at the Independent Living Center. Mary founded one of the first ALDA chapters, and remains active in ALDA and other voluntary organizations.

Everett Chard began professional life as an assistant professor. After becoming deaf, he turned "nonprofessional", moved and worked, finally settling in with a long-term job at Honeywell. His real life is outside of his career, like ALDA/MN, and looking for a farm.

Lee Perish

Thank you for coming to our panel discussion on success. As you can probably tell, I am nervous. If I can manage to get through this without too many blunders, I will consider myself successful. On the other hand, if I manage to put you, the interpreter, and the courtroom reporter to sleep, I will consider myself even more successful. I can then patent myself to cure insomnia.

My hearing loss began when I was in grade school. The district nurse, during her appointed rounds at the country school that I attended, tested my hearing and noted a hearing loss. However, my parents and I were not informed of this but discovered it much later when I went to college. The progressive loss of my hearing over a ten year period was so gradual that it was not until I was a senior in high school that my hearing was
formally tested. During my sophomore year, I remember that our entire class had our hearing tested. I told the school nurse that I couldn’t hear the test sounds but that I could hear the band practicing downstairs. That was clearly not a very professional method of testing. The nurse made some comment to reassure me that my hearing was “probably just fine”.

Whenever I had a cold, I noticed that if I stuck my finger in my left ear I could not hear what was going on. During my senior year of high school I had to miss some of my classes because I had developed tinnitus and was not sleeping at night. It finally became so bad that I went to our family doctor, who then sent me to a specialist in a town 75 miles away. I found out that I was completely deaf in my left ear and that the loss in my right ear was severe. My initial reaction was one of surprise and shock.

Thus began years of audiological testing, trying out different hearing aids, and several unsuccessful surgeries to try to return me to “normal”. The gradual loss of my hearing continued until approximately six years ago when I could no longer use a hearing aid. I was deaf! Actually, being deaf was easier than being hard of hearing because too many people completely misunderstood that a hearing aid did not give me 100% hearing, and they expected me to function as a normal hearing person. Also, I was no longer straddling the fence between the two communities.

I started sign language classes a couple of years before I became completely deaf, and that was the key to my continued success. Most Americans link success with careers, money, marriage, and/or status. My link to success began when I became physically independent of the physical assistance that I had received from my family and that independence influenced my perspective of the meaning of success. Since your own deafness or hearing loss has occurred, many of your ideas of what success means has changed or perhaps needs to change. For me, deafness was a plus in my pattern of success. Perhaps you thought that your career required you to have excellent hearing. In reality there are few jobs that cannot be adapted. What we have to change in most instances is how society views us as citizens. The majority of our society must learn that they have only two choices: either to be dead or T.A.B. That means temporarily able bodied. I think most of us would prefer to be T.A.B. As we become older, all of us function to a lesser degree of independence. Some people may lose their hearing, some lose their sight, some lose their motor skills, and some just keel over. But whatever happens, our lives change, and we need to accept those changes.

I really don’t know why becoming deaf was easy for me to accept. It was harder for me to accept my grey hairs; those I have been known to dye. My view of success has not had to change to any extreme. I have talked with many people who tell me that they had to confront their deafness and change their definition of success. I think that my philosophy of success has remained constant because I have always had a physical disability, have always been challenged, and continue to be challenged. For me, success means satisfaction with both my personal and professional lives. I am now, again, a professional volunteer. I say again because for years I volunteered my time, efforts, skills, and talents to various agencies. When I became a tax-paying member of society, I continued to do volunteer work but to a lesser degree. I admit that I was not happy with having to give such a large portion of my wages to Uncle Sam, but I figured that nothing in life was perfect. Then I lost my job. In fact, the position does not even exist anymore. It disappeared into a cloud of budget cuts that have been hovering over our country. I hope to find a new job soon. But I also know that my work as a professional volunteer is satisfying and successful enough to balance out the stigma of being unemployed. Success is not a goal to be reached, but a path to be traveled.
Perhaps if I give you more background about by successes, you will understand my outlook. My first experience with success came with becoming physically independent from my family and attending college. My college years added structure to my view of success. I remember the great satisfaction I felt when working on a political campaign as coordinator for a local candidate. This candidate was running for state representative in a district that was his political opposite. He lost the election that year but won in the district territory that I was responsible for covering. We won the battle and lost the war, but that did not diminish the fact that we had worked hard enough to win what was supposed to be a completely unwinnable territory. Success!

After college, I entered the job market with high expectations but no experience. I began making inroads, but then a multitude of problems developed related to my hearing loss. I was unable to do any kind of work for a while. During my recovery, I got involved in volunteering and found great satisfaction in doing service for others. At first, I volunteered for a few hours a day, several days each week. It wasn’t much, or very exciting. Still, it satisfied the work ethic that I had instilled in myself. I later moved to a city that was more accessible, which increased my independence. It was at this point in my life that I connected with a person who completely changed my opinion of volunteerism. This woman nurtured the belief that I was not just a volunteer, or only a volunteer, and that a person’s job does not necessarily define who that person is. Volunteer work is work! There were many occasions that I worked 30 or even 40 hours a week.

Volunteerism can also be used as a stepping stone to a career. For myself, working as a volunteer has lead to two paying jobs. These jobs would not have been offered to me if I had not been a volunteer, or deaf and had known sign language. I can honestly say that they were the best jobs that I have ever had. They challenged my mind and my resources. Volunteer work has given me the opportunity to make many new friends. I have also received several prestigious awards and numerous honors for my work.

The most satisfying aspect of my volunteer work has been knowing how much my talents have helped others. It is a wonderful feeling! I feel that I am a successful person because I am satisfied with what I do and who I am. Christopher Morley said “There is only one success — to be able to spend your life in your own way.” That does not mean that I have the right to shoot a few people who are making my life difficult, but it does imply that how I live my life is more important than accumulating possessions, obtaining prestigious job titles, or even finding a husband. I wish you all the best and I know that you can achieve successes in your lives. I also know that nationally ALDA will continue to be a success. The reason has to do with this greeting card. The cover says: Knock! Knock! Who’s there? Alda! Alda who? and inside the card it says: Alda people and it has a number of strange looking characters that are typical of ALDA members. So, we’ve made it in the greeting card business. Thank you.

Sue Hajiani

Hi I’m Sue Hajiani, a late-deafened adult from Minneapolis, and a charter member of the ALDA chapter there that was started by Ev Chard in 1989.

That sounds pretty simple, I am sure, but it took me a life-time to get here; to the point where I could look someone in the eye and say, “I’m deaf” and make no apologies for it. Ev has told me to talk about success but first I have to digress a little bit and talk about denial.
I was born hard of hearing I think. No one recognized it, but my family told me stories about how, at age two and a half I said, “Santa Claus has sunny set” meaning funny feet of course. They thought it was cute but as the only child of two middle aged parents, I was supposed to be perfect and it must have been easier for them not to think about that too much. The kids at school caught on long before the teachers did. They admonished me not to say, “what?” all the time and knew right way where the message had gone away when we played telephone. Now that I think of it, the point of the game was miscommunication. And who is better at miscommunication than a deafened person? But my classmates fell on me with anger and pointing fingers when I spoiled the game.

So I learned to bluff. I faked it. I memorized the spelling words forwards and backwards so that I could get 100% and a gold star, and pass for hearing. I was 10, the first time a teacher caught on about my hearing loss and sent me for testing. The test showed a definite hearing problem and the doctor recommended that I sit in the front of the class. That is what I did for the next 14 years. I got A’s on my report card and hung on to my status as a hearing person. In college, I majored in journalism but I think that subconsciously I knew that I would not make it as a newspaper reporter even though I never consciously admitted that to myself. So, I decided to pursue a master’s degree in political science. I reasoned that I could get a job as a publications editor. All this time, my hearing was getting worse and worse, but very gradually. I knew that it was happening, but I just couldn’t face it and besides, I was a great success at getting by on my wits and my great lipreading. Everyone had very high expectations of me; my family, my friends, and my professors. I definitely wanted to compete and succeed in the professional world on equal terms with my hearing peers.

After graduation, I took a little detour of 10,000 miles and 10 years by marrying and moving to Iran. The Iranians did not mind that I didn’t always understand them, either in English or in Persian. I could always pass it off as not knowing their language, and besides, they needed my English skills. I worked for the copy desk of the Iranian English daily Kayhan for several years. I was sorry that I was not writing and traveling to the provinces to cover the Kurdish rebellion, but things were also exciting on the copy desk and I began to get some personal satisfaction or success (I promised Elv that I would use that word) from my professional skills. But mentally I was still carrying a torch for being a great reporter, and I felt disappointed with myself.

Just before Ayatollah Khomeini came into power, I returned to the United States with my family and started job hunting. There was a recession and no one was very impressed with a very hard-of-hearing person whose curriculum vitae included copy editing in the Middle East. Their knowledge of deafness and the Middle East were about equal.

It took me over one year and three vocational counselors to land a job at Honeywell. At that point I was not thinking about success; I was just thinking about working. I had two small children, and my husband was stuck in Iran along with most of our possessions. The employer at Honeywell asked if I could edit airplane manuals and I said, “absolutely”.

I am a graduate of Iowa State University of Science and Technology and have taken numerous courses in the sciences. Of course, I didn’t know the difference between an altimeter and a gyroscope. I also told them that I was hard-of-hearing, but at that time, there was a policy in the human resources department to promote the hiring of disabled individuals, so I got the job. It wasn’t what I wanted or what I had in mind at all, but I thought, “Well I can always apply for something else in a different group later.”

I started overcompensating for my hearing loss again. I put in a lot of overtime, volunteered for hard projects, and when the phone rang, I surreptitiously left the bay so that someone else could take the message. I can see now that this was not the right
approach but ALDA was not yet born and I really had no one to support me or to talk things over with. According to my plan, I began applying for other Honeywell jobs. I must have applied for 60 or 70 before it occurred to me that I was pursuing an impossible dream. I went through a period of bitterness and unhappiness. In spite of many interviews, not one supervisor ever checked my track record in the company or called my supervisor to see what my skills were like.

During this period, I think I made the first real step to success for me and not for someone else. I became active in the first Honeywell Disabled Council and met another deaf employee. He persuaded me to get my first hearing aid, and it was only 25 years after I first realized that I had a hearing loss!

I was also involved in volunteer writing for non-profit organizations at this time and won a few prizes that made me feel much better about myself. The volunteer work provided me with a great deal of satisfaction and many friendships, and after a while, it was not just something that I was doing to beef up my portfolio for the next interview. I became more up front about my needs and negotiated with my boss for a TDD. He’s an engineer, so the equipment intrigued him and he was fairly supportive of that.

Meanwhile, the company was downsizing, and many people were leaving. After a long tenure, I had become something of an expert in my group. I was promoted to the lead editor position, where I was responsible for the work and training of four other editors. Again, I relied on my expertise and ability to go the extra mile and I really began to enjoy my job. For the first time, I began to feel satisfied professionally, and I put my old dream on the shelf. The editors were good about making accommodations when talking to me by getting my attention first, sending electronic messages. I was in the habit of writing down instructions for them anyway and getting my own project instructions in writing, too.

About that time, Ev Chard returned from ALDACON I, and he was flying high. He suggested that we start a chapter in the Twin Cities. At our first meeting we sat and wrote notes to each other. Ev signed and spoke, but I didn’t know sign language. I decided to learn. I’m still working on my sign language skills and recently negotiated an agreement with the human resources department to pay for an interpreter for two to three meetings per month. I have to emphasize here that 90% of the accommodations that have been made for me at work have come because of my initiative and persistence. I used to feel sorry for myself because the company was not more forthcoming in that area, but now I feel comfortable with the idea of making my needs known and insisting on reasonable accommodations. I figure that I have the ADA to back me up if things get tough, but it hasn’t ever come to that.

So, what have I learned about success along the road to middle age as a late deafened adult? I guess it’s mainly that there is not one big success that goes on and on, but a series of smaller satisfactions of different character. For me, it is expertise and respect on the job, friends and creativity in the non profit world, fun at ALDA, my family, and all of my various interests. I might have learned this sooner without having the denial that deafness created in me, but then again, maybe not.

In summary, I would like to draw a few general rules that what worked for me. I know that every person’s experience is different depending on the age and circumstances of the loss, but here goes:

1. Find something you are good at and keep at it.
2. Network with others for support.
3. Acknowledge your needs and negotiate for acceptance of them, in both work and family
life.
4. Try new things. Let go of old things, groups, etc that do not work for you any longer.
5. Have fun along the way.
6. Remember that hearing people have frustrations and disappointments too.
7. Don’t wait for others to define you, set your own terms for success.

Mary Skyer

Good morning. My name is Mary Skyer, and I am going to give you a description of how I got “from there to here”. At the time I became deaf, I was 24 years old and had been a student at Illinois State University. I’m 38 now. I was a mediocre student. I had no goals. I went to college because of my friends did. I had no idea of what I wanted to be when I grew up. It took me a long time to declare a major, but, I finally settled on speech pathology because I was fascinated by the process of communication. I quickly learned two important things after I had made that decision: I was bored to death with how speech is produced, and that my hearing was rapidly deteriorating for unknown reasons. I could not foresee a future in that field for me. I was also very sickly at the time, so I had missed much of the course work. Still, my academic counselor advised me to stay with speech pathology. I knew in my gut that it was the wrong profession for me so I changed majors to home economics with a concentration in family and child community services. At that time, I had to leave the university for surgery; which left me deaf in one ear and paralyzed on one side of my face. I returned to school as soon as I could because I wanted to finish my bachelor’s degree before I became completely deaf. It was obviously not meant to be as I had to have more surgery. I was deafened and had full facial paralysis. The facial paralysis was harder to deal with, I think.

When I was strong enough, I finished my bachelor’s degree, and then worked two part-time jobs; one as a seamstress and one as a hospital aid. It was awful; no matter what I did, how fast I did it, or how well I did it, it was not enough. I used to love to sew but I rarely pick up a needle and thread now. The hospital scheduled me for full time work, but technically I was not a full-time employee and I had no benefits. The hospital refused to hire me full-time because I could not use the telephone. I was overwhelmed with frustration and anger. I could not cope with anything. I started to see a counselor to help me sort things out and make some sense of my life. I learned how to take a risk! I even filed a law suit against the hospital. It took over a year for the suit to through but, I won. I knew I would not stay there. It just so happened that my sister had read about a program in San Francisco that trained people to teach independent living skills. I did not know what it would entail, but I took the risk and went out there one summer to study. The people I worked with had minimum communication skills; they could not read, write, or sign. My students had their own communication system. It was very exciting and challenging work, not depressing in any way. I became addicted to the work! I ended up moving to San Francisco to finish the program. I discovered that many of the clients also had emotional problems and I realized that I needed to add to my skills.

I entered the rehabilitation counseling program. After I completed my master’s degree, I worked with people who were deaf and blind. I loved my work but the work environment was not healthy. I was again dealing with feelings of frustration and pain. I wanted out of my job and had been pestered friends for job leads in the San Francisco area. The place I had been working refused to provide interpreters for me so whenever I went to an interview I did not bother to request an interpreter. Crazy, huh? To be honest my speech reading skills stink! Fortunately, during the interviews I understood very well. I was hired
at the Independent Living Resource Center in June of 1989 and have been having a great
time there ever since. It's exciting, challenging and very hard work.

For me success meant that I had to learn to be true to myself and this meant getting help to
work through my problems. I learned to adjust to deafness, to take risks, and to laugh,
especially at myself. Like Lee, I am stubborn! My tenacity got me through, but I am also
willing to roll up my sleeves and work hard. I grew up trying to please everyone else and
now I do what I think is right for me, even if it is a little crazy.

**Everett Chard**

**Mary Margaret Sharp-Pucci (holding dictionary):** Before he speaks, Ev wants to take the
oath. "Do you promise to tell the success, the whole success, and nothing but the success?"

**Ev:** Sometimes!

I have to do this map of my life in 15 minutes, so I will speak, not sign along, because it
goes faster that way. I will pass this map around because there is no flip chart for my life.
The map is a simple graded diagram (A, B, etc.) covering four areas of life: social,
intellectual, athletic, and individual/independent. It is graded at roughly 10 year intervals.
At age 10 I had a brain tumor; at 20, there was the first recognition of hearing loss; around
30 deafness came; at 40 I was married; and I am about 50 years old now. I received an A
in the social area, a B in intellectual and athletic areas, and a C in independence at age 10. In
the pits after becoming deaf, I have an A in the intellectual and independence areas, a C+ in
athletics, and an F in social.

Once upon a time, I was sailing from Japan to the U.S. on a freighter while the U.S. was
still fighting in Vietnam, and I asked the Japanese captain, "What can you advise us?" He
said, "Don't walk on mud." I felt sometimes that living my life was walking in mud. But
not at the beginning.

I was born on a "block", in a small town, and there was a group of kids growing up
together. One kid's parents would watch out for all of them. In this place no one stood
out; the other kids would bring him down. So, even though I read a lot and was kind of
screwy, I didn't get away that far.

At age 10, I had a brain tumor removed and the tumor took me out as nothing else could. I
had poor eyesight; double vision, no depth perception, and multiple dominance. I couldn't
catch a baseball well. I sized up the situation unconsciously and dove into making myself
shine at school. I have the facts. These are my report cards from St. Gilbert's school. The
Sister teacher was a top nun, and she gave me B's and sometimes a C for handwriting. I
received a good in catechism so I was okay. Part of this change in my behavior was
recognizing that I could not compete in athletics. Before age 10, I was chosen for
shortstop and pitcher; after 10 I had right field. I was able to learn well in high school.
I got A's and one B. I didn't get a letter for sports and I had no dates. I received two B's in
college while all of the rest were A's. The dictionary received my award for outstanding
male senior. I had a few dates. I hoped the hearing loss wasn't real.

You'll notice that I don't talk about deafness. I thought privately and spoke nothing. My
feelings were buried underneath the surface while I paid attention to the theories of
government and the written word. My stubbornness continued through graduate school in
Berkeley, and through research in Kenya for my doctorate. All the while I ignored the
doctor who tested my hearing and said, “You will become deaf and you had better change your career.” Instead I changed the future. I said, thought, and lived by the premise that I had no future; that it didn’t really matter.

A college in Washington State hired me to teach. I was so scared of teaching that I became sick before each class. This continued until both the students and I got comfortable with my style of straight lecturing with no questions. I faced the fact that I was becoming deaf and I ran away. I could deal with deafness; I could not deal with its consequences. So, I dealt with them here in my head. I dived into a conceptual world where I thought about the United Nations, political development and theories of pluralism. I even thought about the concepts of deafness. I refused to feel. I became a hermit; I avoided people. I had a chance to learn sign language and I turned it down. A deaf student asked me how to become a college teacher, and I grinned. I quit teaching in 1974. My tenure was up; my future held nothing.

I lived in Seattle for two years. I was so isolated that if I talked to someone beyond saying “Thank you”, I felt sociable. My dream was to become a writer like J.D. Salinger and to live in the woods. Geography can explain how sunken I was. Four blocks east of me, up the hill, was the Seattle Hearing, Speech and Deafness Center. Two blocks down the hill was the deaf program at Seattle Community College. I ran by both, but never stopped.

The point of this dreary cut from my life is that I had tossed away any human contact. My parents, family, and friends lived about 1,600 miles away. I made no new friends. I dated twice in about 10 years. I tossed out my living audience and ran away; I couldn’t face the risk of their knowing me. I clung to my conceptual audience. I had books to read, books to write, ideas to think, and fantasies. I did all right there. I wrote sparkling letters, but never met their readers.

Looking back, I can’t see why I did that. It’s so unreal; I was so unreal. I used to think, that with all of these degrees and analytical tools, how could I have been such a dope? And an answer is, because I was so damn smart. I need the block kids, not adults. Instead I got books. What happened? I didn’t go back to the block. I learned sign language in 1976. They were a paltry few signs, but my yen for academics kept me going to sign language classes in St. Paul, meeting people, and going to the deaf club to play bingo. Still, I had no dates.

Slowly I went into rehabilitation; social-psychological, not vocational rehabilitation. I met my wife there. First, we had a date, and was that success! Next, we lived together. I proposed; Rita said yes. Now, Rita was a sign language interpreter, and we got into arguments more and more often, and when they got going, I’d ask Rita to slow down her signing. Rita would sign, “You can speak; I can hear.” Yet I couldn’t argue; I’d diagnose, I’d analyze but still I did not feel. She booted me into therapy and after a year and a half my shell wore down and we started talking. Our marriage went down really bad, but I considered it good for me. I met a lot of interpreters; since Rita was president of the local registry of interpreters and I found them to be a bit of a block, the audience. That expanded through my work as a proofreader at a printing company and in my volunteer work and other activities, and even the University of Minnesota.

That time during the early 1980s, I began to see what had happened, and what might happen. I became more and more aware and sensitive toward myself and others. I recognized that I had used deafness, this “no future” excuse, to protect myself against the risks of real life, the rejections that go with it, the obligations and the commitments. Deafness was simply my presenting symptom for problems much deeper than not being able to hear.
So, by the mid 1980s I had started making friends, and enemies, and relationships. I even became executive director of a non-profit deaf community organization. The problems caused by my miscommunications were enormous, my errors were numerous, and so were the findings of the Board. It was a great risk; I didn’t realize how large of one at the time. After a year, the Board fired me. It was a success. Then I began dating an MBA, I could not find a job, and in no way was that a success.

After six months, I found a part-time job with Honeywell that became a full-time job a year later. I take care of paper, that is, of the records of a division of Honeywell. It’s not a career job, but it pays enough to be comfortable and to save some money. I have a lot of voluntary committees that I work on. Somehow, and over the past five years, success has become a “nonissue”. It certainly would be if my life dropped off. With these committees, my friends and enemies, my coworkers and others, I have a mixed audience now. You may see how I became trapped in academics and with intellectual audiences. It eventually narrowed to only me and my head, and I followed it out of the real world. I’m back in now. My neighbors and landlords are deaf.

Now, I can see that it is impossible to become successful without a community, or an audience. There is an absence without it. Two years ago, when starting ALDA in Minneapolis, I had hoped for something like a community. That is a good reason for ALDA and for this conference. It provides a community, temporary as it may be, and an audience. Now that’s successful.
Late-Deafened Adult: After 35 Years, What Sayeth Thou?

John J. Gavin

John J. Gavin, Ph.D. is profoundly deaf. After losing his hearing in 1956, he returned to school and obtained his doctorate in bacteriology. He retired last year after a successful career in the pharmaceutical industry. He has been a long time advocate for the education and employment of the handicapped.

Good afternoon. You probably wonder who I am, or who am I. I am John J. Gavin, a husband, father, son, brother, friend, advocate, microbial biochemist, and profoundly deaf man for 35 years.

What is deaf? It is a descriptive term covering a broad range of hearing deficiencies, including speech problems related to the inability to hear. It refers to the loss of the essentials of communication to one degree or another at three distinct levels: the symbolic sounds of speech and language; the signal identification of vents in the environment; and the primitive recognition of being in the sense that one is part of an environment and attached to something real.

What is deafness? It is the most profound psychological insult that can be inflicted upon a human being. Despite protests by some people, deafness is not merely a difference; it is a pathological condition. Although the causes may be diverse, the direct result is always the loss of a primary sense. Current politically correct speech labels deaf people, hearing impaired.

My lifetime as a deaf person has covered a period from apathy to tolerance of physical handicaps. My views should be seen through the prejudiced eyes of a survivor. I do hope that my observations will be of help to many of you.

Over the past 40 years, I have talked to a large number of groups, but this is the first time the audience was predominantly deaf, like me. This has caused me some concern. I recall a story about two deaf gentlemen who were having a discussion. It seemed one of the men talked on and on and on, while the other man was unable to get a word in edgewise. Finally, the first man stopped talking. When the other person started, he turned off his hearing aid!

I thought you might like to know how things went for me, one who has lived in the silent world for almost two generations. I will try to avoid pontificating, but the end result is,
of course, my version of my yesterday. In fact, it might be termed as sort of an oral history by a participant, unwilling of course, but a participant nevertheless.

At age 69 I have managed to survive a depression, a couple of recessions, the Army, a war, a service connected disability, sudden deafness at age 33, the loss of my job because of the onset of deafness, graduate school, retirement and being the father of 9 children.

I have been profoundly deaf since 1956 due to an adverse drug reaction. The wheelchair bit is the result of a football injury followed by overseas service (England, France) in the Army during World War II. My physical condition since my medical discharge in 1945 has gone through many changes. Body casts, braces, canes and crutches and, about 4 years ago, the wheelchair, have followed several operations.

When I read the announcement in ALDA News requesting the submission of potential presentations dealing with “Facing Deafness”, I thought I should volunteer to share my experiences. Perhaps I can provide some insight on how to adapt to living in the “silent world.” In theory, there is no problem; deafness does not go away. There is not very much you can do; one adjusts and gets on with life. As a practical matter, adjustment can be a dirty word. Read some of the comments and letters in ALDA News. For extreme reactions, read The Disability Rag. For the first couple of years I, too, had my moments. Witness a feeble attempt at verse during 1957:

**ON BEING DEAF**

Condemned
for a lifetime to a prison whose only walls are silence
the soul soars to extreme heights of anticipation but
nothing for a lifetime is what it appears to be as in the quiet the soul interprets what it wants to be hardly ever what really is so imagination for a lifetime plays tricks upon the prisoner and the soul quite quickly sinks to the depths of despair often.

What I have to say may be of help to some of you in adapting to deafness; for others, probably not. However, I do not pretend to be academically qualified as a rehabilitation expert. Still, my everyday experience with physical problems over the past 50 years should give some credibility to my remarks.

I do have a warning. You will have to decide whether any part of what I have to say applies to your personal situation. It is imperative that each individual work out their own personal salvation. An example of what I mean comes from travels last summer. We stayed at a hotel where the sugar packages in the dining room were made by Kraft®. On each packet was a message. One stated: “We are all manufacturers - some make good, others make trouble and still others make excuses.” If you read the writings of people with disabilities, you will have seen examples of each type of product. Then there are people who don’t want to improve their situation. Their philosophy is, “I love being miserable.”

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I am a handicapped professional and not a professional handicapper. My views do not always (hardly ever) reflect those of the accepted leaders of the deaf or the handicapped communities. I attribute this to my being a late deafened adult. I knew and knew what I wanted out of life. As an adult, I did not have to listen to those individuals who believed they knew what was best for me. In fact, I have been somewhat successful because I have done what I wanted to do. My ego also leads me to believe my achievements in the hearing world have been at least as much for deafened people as have the efforts of self-appointed advocates. I have not complained; I have competed and produced. Other deaf individuals have been provided with opportunities because of this. Adults should listen to counselors, other non-professionals, friends, and relatives. Then do what they want to do even though others may not think they should. One very important choice we have is the opportunity to fail. Children do not usually have this option. When they grow up their approach to facing deafness may be based upon how they were influenced by hearing adults. Thus, those of us who lost our hearing as adults have an edge over those who did not.

How do we exploit the advantage of being deafened adults? First, we must have or we must develop a positive self-image. Successful people build strong attitudinal views of their capabilities. While we may have had a good impression of ourselves and our capabilities before losing our hearing, we meet many negative people during the initial period of being deaf. The impact of deafness and the attitudes of close associates can destroy our confidence. So, we must visualize what we think will lead us to success, and then build the confidence to achieve it. One way this can be done is by affirmation. For example:

**AFFIRMATION TO IMPROVE SELF-ESTEEM**

1. I like myself unconditionally. I am happy being the unique and special person I am.
2. I never devaluate myself through negative self criticism.
3. I am fully alive and have an abundance of good health and energy.
4. I thank God for the people in my life and delight in them.
5. I am free to be the person God intends me to be.

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We have to be our own cheerleaders!

When my hearing disappeared everyone seemed to know what deaf people could not do; few, if any, knew what a deaf person might do. My experience with rehabilitation experts was less than ideal. (I hedge here! This is based on my personal experiences between 1956 and 1958. I have had no professional contact since then. Further observations and "tales" have not impressed me that real progress has been made. I am sure there are specific instances of close to ideal advice provided to clients by many preceptive rehab people.) What they thought I should do and what I thought I was going to do were not compatible, so I decided on a self-help program.

It was relatively common for a deaf person to acquire the nickname, "dummy", even those who might just be hard of hearing. Many hearing aids were designed for appearance, for example, small and hidden, rather than function. Hearing aid dealers were very defensive and would hardly ever tell a customer a hearing aid would be of no benefit. Advertising was mostly of the "you can hear again" type. For hard of hearing folks, hearing aids can be a blessing. For the profoundly deaf, wasted bucks. I have a drawer with several hearing aids that never worked for me. I did wear the earpiece and
the cord when I traveled. This showed I was deaf and might not respond to questions or just plain talk. It worked most of the time. However, one memorable time it didn't. I was on a flight from New York to San Diego. I had just made the flight; my baggage didn't. I was huffing and puffing when I reached my seat, and I wasn't in the best of moods. My seatmate was a nice old lady of about 90 or so. She started talking as soon as I sat down. You may not believe this, but in between sips of scotch (neat) and eating, she talked just about all the way. I did not understand a single word. I did nod my head and say, "yes, that's right" a few times. When we arrived she introduced me to her daughter and mentioned what a nice conversation we had had on the trip. So, you can make someone's day without trying or knowing what you are doing!

The first two years after my hearing disappeared were difficult not only for me, but for my family as well. I certainly wasn't easy to live with. Some of this reaction was due to physicians' uncertainty as to the cause of my deafness. My hearing might return as suddenly as I lost it. Almost every night I went to bed expecting the alarm clock to wake me up. Part of my reaction was the result of learning many of my scientific peers thought when I lost my hearing I could no longer think. They were difficult days indeed. When I decided to take charge of my life, things began to look up.

In 1956, I didn't know a single deaf person or where to get help. My physician did not have any advice for me, nor did the teaching hospital where I was tested and tested and tested without any diagnosis. However, I did have a young lady friend, one of my scientific peers who was active in her church, and who inquired there as to where I might get help. My first association with deaf persons came as a result of her efforts. I registered for lip-reading classes at the New York League for the Deaf in Manhattan. She also volunteered to read scientific literature for me so that I could hone my skills at lip-reading scientific terminology. That was the launching pad, but it didn't save my job.

Once again I was lucky. Another young lady peer learned that a physician doing clinical research was looking for someone to assume the responsibility for the required laboratory analyses. She recommended me, my former employer certified me as competent, but deaf, I was interviewed and hired. It was a rewarding eight year relationship for both of us. He accepted me as an equal and encouraged me to go back to school part time for my doctorate. I provided him with quality data and ran the operation in his absence. We published a number of papers together and I obtained a patent on a cell culture apparatus.

The vast majority of citizens were not very sensitive to the concerns of the deaf or the handicapped in those early days. Professors seemed to be the most obstinate. I applied to a number of schools in the immediate area. The comments were much the same; variations on the theme, "you can't get a Ph.D. if you can't hear." Finally I went back to my alma mater, Rutgers University. Dr. Umbreit, the Head of the Bacteriology Department, had a single question, how would I get the lecture material? I told him I would carry a tape recorder and my wife would transcribe the tapes. He said, "Fine, let's give it a try."

We can all benefit from support and encouragement. My entrance into graduate school brought both into focus. Dr. Umbreit provided an opportunity for me to compete with young and talented students; no special favors. He consented to be my thesis advisor. In that capacity he accepted a real problem. During our three year association I was never able to lip read him. He wrote and wrote and wrote. His patience with me went far beyond the call of duty. He also provided me with an opportunity to fail.

This is the second time I have used the phrase, "an opportunity to fail". You may wonder what I mean when I say that. It goes back a long way. Gladstone (1809-1898), a British
statesman and Prime Minister, is reputed to have defined success as the ability to go from failure to failure without becoming discouraged. The underlying truth in this statement is that if we are perceptive, we do learn from failures in our lives; we put them behind us and go on to other things. Inherent in such a definition is the question of how does one develop the mental toughness required to reject rejection and continue to expose one's psyche to further rebuffs. For most people this is accomplished on a trial and error basis as they move through the various stages of their lives. They grow in wisdom and gain the inner strength they need as they experience both success and failure in putting their acquired knowledge to the test of practicability. The direct experience of personally meeting problems teaches people what observation of others could never have taught. They have been provided with an opportunity to fail. Many deaf persons are denied the opportunity to develop in this manner. Relatives and friends tend to be overprotective. Potential and/or actual employers are reluctant to take risks. Some of them seem to have a desire to shield deaf persons from the realities of life. They do not want deaf persons to do anything in which they might fail. This is characterized by a "father knows best" attitude combined with a stereotypical judgment of what can and ought to be done. The approach is negative and emphasizes what can't be done. All of this generates feelings of frustration and anger in deaf adults.

Often the anger is directed both outward and inward; outward towards those perceived as intruding into personal affairs, and inward because of their inability to express the they feel to those who are trying to help them. What it does is reinforce a general feeling of inadequacy, something deaf people do not need.

As I embarked on my new adventure, I realized scientists must present data and theories in public forums. To learn to modulate my public voice and to gain experience speaking in public, I volunteered to be program chairman for two organizations. This meant I would have to talk at least twice a month, introducing the speakers I recruited. In addition, I volunteered to talk to at a variety of affairs on subjects within my competence. Because I needed the experience I didn't charge a fee, which made me popular in some fraternal sectors. My wife spent several hours with me rehearsing the presentations. When I first started, I shouted. It only took a couple of minutes before the toll on my throat led to correction!

Another experience was traveling. It was about 35 miles from my home to the university, 45 miles from home to work, and 60 miles from work to the university. Since I worked and attended classes at the same time, some days I went from home to work to school and some days from home to school to work. This kept me from getting dizzy! I was at the mercy of scheduled lectures. Things were somewhat easier when I started my thesis work as it became my decision where I would be and when.

In 1961, I applied for and was awarded a three year United States Public Health Research Fellowship. My employer agreed to make up the difference between the award stipend and my salary if I continued to oversee the laboratory work being performed for on-going projects, and I agreed. Of most importance was the significance of this award to me. At that time, there were no set asides; everyone competed under the same conditions. The fact that I had been successful in open competition was very encouraging. I knew that I could do science as well as anyone else. My great adventure had begun.

It was an exhausting time for my wife. She was in the midst of caring for our growing family of seven and 7/9ths, and took on the job of transcribing my classroom tapes. Calculus was first! It wasn't real bad- I baby sat while she transcribed. But calculus is difficult even if you have a math background better than that required of a registered nurse in 1943. It was the most demanding course I took as a graduate student. I just
barely passed. But that was all I had to do because it was an undergraduate course, a prerequisite for physical chemistry. I only needed to gain some knowledge of mathematical relationships. However, it was a great exercise in self-discipline.

We managed to make it through the next couple of years. I was awarded a Ph.D. from Rutgers, The State University of New Jersey in June 1964, and I was the first deaf person to do so. This was the same week our eldest son graduated from high school. The local papers had several stories on the combination. My message at that time was simple. David Wright expressed it best in *Deafness*:: "Every disability offers the same alternative: either it dominates you or you dominate it."

My return to the pharmaceutical industry occurred later that month. I had been hired as a Senior Scientist and Head of the Bacteriology Research Group by a leading drug company. My job wish list had Professor as my #1 choice, but it was not to be. The refrain had changed from "you can’t get a Ph.D. if you are deaf," to "you can’t teach if you can’t hear." I didn’t appreciate the discrimination at the time. I still don’t, but now I understand better. Deafness was not something with which academics could readily empathize. The end result, however, was greatly in my best interest!

My first job was a learning experience, not only for me but for others as well. I found many of the people who reported to me did not know how to handle a supervisor who was obviously deaf. In a science laboratory supervisors must have the respect of the troops. Otherwise they fail. Good people will find other jobs and leave. Mediocre talents stay, but bitch most of the time. Morale and research efforts suffer. So, my first action was to demonstrate I was good at science. My motto was, “anything you can do, I can do better”. I spent time in proving this, and after a while, my co-workers were convinced.

Another important guideline was developed. I had the idea I could anticipate what people were going to say once I knew them well enough. I was wrong and I made several mistakes. Now, I happen to like limericks. When I came across this one the message was clear:

*I know a beautiful lass*
*Who has a magnificent ass*

One could make a number of wrong conclusions if projections are made now because the rest:

*It is gray,*
*Has long ears,*
*And eats grass;*
*The magnificent ass*
*Of this lovely young lass.*

offers a different perspective. I also learned I am not very good at politics or semantics.

My first job had lasted about 18 months when I was approached about a better position. I listened, because I had experienced obvious discrimination in terms of promotion. The most important element in my decision to leave, however, was the opportunity to work, again, with the physician mentor who encouraged and supported my efforts to obtain my Ph.D. He had become Vice President and Medical Director at Dome Laboratories, the pharmaceutical division of Miles Laboratories. I returned. The next 25 years were important in establishing my philosophy with regard to the education and employment of the handicapped with an emphasis on the deaf population.
I became concerned with the problems of handicapped persons. Frequent travel on company business made me realize there were few, if any, visibly handicapped scientists. I didn’t even see one with a hearing aid. It was difficult for me to believe I was the only one, but I could not find any others to refute this observation. I was to learn that there were several companies in the chemical/pharmaceutical industries that employed people with handicaps. Among them are du Pont, Xerox, and Hoffman-La Roche.

The American Association for the Advancement of Science (AAAS) was in the process of establishing a program to promote, support, and advance women and minority persons in science. When I read of these efforts in Science, I wrote asking whether they planned to include handicapped scientists in their program. They didn’t, but agreed to consider it.

Bill Carey, Executive Director at that time, and the late Margaret Mead were ardent supporters of handicapped scientists. They insisted something be done. The Project on the Handicapped in Science was the result. From the beginning the Director, Dr. Martha Redden, asked disabled people who were in science to identify themselves and serve in a resource group. We then organized a symposium for the AAAS annual meeting in 1974. Three of the six participants were deaf and the keynote speaker was Director of the Deafness Research and Training Center at New York University School of Education, Dr. Jerome Schein. The proceedings were published in Chemical Technology, Volume 5, December 1975. This was the first major scientific publication concerning handicapped scientists. The Foundation for Science and the Handicapped was organized shortly thereafter.

The AAAS program continues today, but there is a difference as far as the deaf are concerned. Dr. Redden left the AAAS and her successor is an advocate of the A.G. Bell Association. Much of what comes out of the AAAS now relates to the oral deaf. A publication, Our Kids Magazine, had a special issue on hearing impaired people and science. Forty-four hearing impaired scientists, mathematicians, and engineers were listed as role models. Not listed was a deaf individual who is, in my opinion, the finest deaf scientist in this country, Dr. Donald Ballantyne. He is known internationally for his work in the transplantation of vascular beds during reconstructive surgery. He signs. Discrimination of this type is atrocious. The playing field should be level.

I am sure I have been overlooked for jobs due to my hearing loss. But deafness has not interfered with my employment or with my being promoted. In only one case was my hearing loss a factor in promotion, and as I mentioned before, I left that company. The biggest problem, as I see it, is the inability to move on to improved (expected) opportunities. Scientists often relocate to other companies because of changes in the direction of research. I think I was unable to do this. I was moving ahead rapidly in the Research Division when the president of the division died. He had backed me completely while his successors put forth their best efforts to remove me. For a number of years it was a draw. If I could have found comparable employment, I would have left.

I can’t state the lack of interest by other pharmaceutical companies was due to my inability to hear. I was pushing 60 when this was happening. The combination may have limited my chances. Still, when I did retire at 62 and moved to Virginia, I had no problem finding a very good job. I worked for that company for six years until we decided to retire for good.

During the 25 plus years I worked, I was also active in the handicapped cause. I wrote a number of articles, including a critique of the Supreme Court’s decision in the Davis case. I served on the Deaf Advisory Committees in two states, Indiana and Washington,
and on the Governor’s Committee for the Handicapped in Washington. I was a Founder trustee of the Spokane Deaf Services Center, and served as the Mayor of Spokane’s Advisor on the Handicapped. I lectured as an Adjunct Associate Professor of Microbiology at the University of Notre Dame and served on the thesis committees of several graduate students. I lectured, advised graduate students and was involved in developing a curriculum for an undergraduate program in molecular biology as an Adjunct Professor of Biology at Eastern Washington University. So, as you can see I have had an interesting and full life for one who is profoundly deaf. I would like to stress I was able to do this without neglecting my family. My non-family activities took place at work and after the kid’s bedtime. My wife often accompanied me on business trips. We managed.

I didn’t do too well in direct involvement with deaf people after retirement. I thought I might be able to contribute something to young deaf people. I was willing to become proficient in sign language. I applied for a position as dean at NTID. They preferred a hearing person. In 1984, I applied for the presidency of Gallaudet. They also selected a hearing person, Dr. Jordan’s predecessor. You win a few, and you lose a few!

You probably would like to know what I have learned over the past 35 years. First and foremost, there are worse things than deafness. The “why me?” response is a legitimate question for a while. At some point, though, you have to discover whether or not you are still feeling sorry for yourself. Remember everyone has problems; some are just more visible than others. Look around. You will find many people - some without obvious physical problems - with whom you would never want to trade problems. Eight years of employment at a very large mental hospital convinced me of that. While there I also learned not to be hasty in my judgments when people are nasty or mean to me; they may be among the “walking wounded.”

Was it easy? Hell no, but it was fun and exciting. Most people have hard times; not all of them have fun and excitement. So that was a plus and still is. But what did I learn? The major surprise was learning that communication is not only a problem for deaf persons, but also of hearing persons. This is something I should have known from observation, however, it didn’t strike me until I became a supervisor. Before that time I was only concerned with me. Did I understand what was being said? When I became responsible for the work of others, the emphasis was changed. Did those who reported to me understand what I was saying? Peter Drucker noted in a 1974 book that communication is the act of the recipient. One may initiate communication, but it is not complete or effective until it is received and understood. This is the reason a deaf individual must make a personal choice regarding their mode of communication. No one, least of all hearing persons - mother or not - has the right to criticize another person’s choice. All of us must remember equal doesn’t mean identical. Differences should be respected.

You may wonder why I don’t use sign language. It has nothing to do with philosophy, but much to do with reality. I know a sufficient number of signs to survive if I found myself on a desert island with only signers as company! I have no prejudice against using sign language. The basic problem has always been other people and scientific terminology. I know of no professional peer, supervisor, or manager who would learn sign language in order to talk with me. Communication has always been my problem, not theirs.

I have used interpreters, both oral and sign language. When slides are used in a presentation, a light is normally required to illuminate an oral interpreters mouth. Close-by peers are not very happy about that. Sign language interpreters were, and I believe still are, unable to interpret most high tech language in Signed English. I think
"Artemisinin, a Sesquiterpene Lactone Isolated from a Chinese Herb has been the Focus of Recent Antimalarial Drug Development Efforts," the title of a paper published in *Annual Reports in Medicinal Chemistry*, 1991, Volume 26 would be difficult to interpret and keep pace with the speaker. The problem can be minimized if you sit down with your interpreter prior to the presentation and devise codes for specific terms, but you must be able to anticipate some of what the speaker is going to say.

I am not alone. A Ph.D. chemist employed by a major pharmaceutical company states he has been losing his hearing over the past several years. Because of this it is difficult to understand what is being said at meetings, it interferes with his ability to communicate with others, and it makes participation in his profession incomplete at best. Apparently he does not believe interpreters will work for him. I don't know this for sure but his solution for hard of hearing chemists is not interpreters. He suggests portable amplifying systems for use at seminars and meetings. I think he means those FM or IR systems. Justification for providing such systems is difficult at multiprogram meetings, like scientific societies. General sessions and award winning lectures might qualify, but the people who finance these things like to hear about numbers and therein lies the problem. What may be ideal for a meeting such as this, ALDAcon III, where the majority of people in a single room are deaf, may not be appropriate at a meeting where few, if any, are deaf. My solution was to carry a tape recorder and have the tape transcribed when I returned to the lab. But even with this system I had problems. There were a number of scientists who did not want their presentation, comments or remarks on somebody’s tape!

Sign language is like every other language; to maintain your fluency you must practice. This has not been possible for me. Over my entire 40 year career I have met only two deaf signers working as scientists, so, I have had no one with whom to practice. I used to read French and Italian easily and German slowly, with a dictionary. I kept up by reading scientific literature in the original. I haven't done this since I retired so I may be rusty. I attended a scientific conference in Czechoslovakia in 1982. A Russian scientist presented a paper in German (poor) that was interpreted for me in English by a Danish friend. This gentleman also accompanied me to Sweden to help me understand another conference's proceedings. (Did you know linguistics estimate there are 4,000 to 6,000 languages in this world; about half come from a single island, New Guinea?)

As I stated earlier, deaf and hard of hearing persons should communicate in whatever mode they wish; those who think differently should keep their mouths shut. There is no best way; it is personal choice and dependent upon the individual goals of the person involved. A case can be made for either means.

Discrimination against the deaf is not just a question of hearing people versus the deaf and hard of hearing. I have been discriminated against more by deaf people than by those who hear. Some of it has come from the "power" people, some from those who sign, and some from those who are oral. I'm not saying it didn't bother me; it did. But I have always been in a position where I could ignore it. Going my own way, without accepting help or depending upon rehabilitation advisors and/or deaf organizations has been an important factor in my life. So, be careful to whom you may listen. You must be selective.

One must work harder than those who can hear if you wish to be competitive in the hearing world. Despite claims of deaf community activists, we do live in a world where the great majority of people hear, about 99% of the world's population. There are many jobs available for deaf individuals who are competent and willing to give a little extra. The little extra also happens to be the edge that puts hearing people on the fast track. In
short, do all those things that have to be done. Try to handle career disappointments well.

Prepare. This might not get you what you want, but not being prepared will surely lead to failure. Agenda are available for most important meetings. Familiarize yourself with the items to be discussed so that you can make a contribution. Don’t worry about being wrong; if you are, there will be any number of people just dying to tell you so. An equal number are ready to tell you that you are wrong even when you’re right. Be tough, be hard, don’t complain or cry in public. Complain only to intimate friends and wait until you are alone to cry. Don’t undervalue yourself or your talent. If you have worked hard to accumulate skills and/or academic credentials, no one will be doing you a favor when they give you a job; you will be qualified. Don’t sell yourself for less than you think you are worth. If you do so, you eventually will become unhappy. Persist. Calvin Coolidge said, “Nothing in this world can take the place of persistence. Talent will not; nothing is more common than unsuccessful men with talent. Genius will not; unrewarded genius is almost a proverb. Education will not; the world is full of educated derelicts. Persistence and determination are omnipotent. The slogan, Press on’’ has solved and will always solve, the problems of the human race.”

Are things better today? In general, I vote yes. But I wouldn’t really bet the ranch the environment has changed greatly. The August 8 issue of USA Today carried an item indicating a number of people in Maryland have protested to the Public Service Commission about being charged 45 cents a month ($5.40 a year) by the C&P Telephone Company for relay services. But we are better off than we were in 1956 and much better off than before that time, even though we didn’t have to worry back then about using the telephone! While there is considerable frustration with what appears to be integration of deaf persons into the mainstream of American society, I am inclined to believe this view may be more apparent than real. There are many more opportunities for qualified deaf persons. It may be promoted by those who have much to lose.

Thomas Sowell, who is Black and a fellow at the Hoover Institution, recently commented on Black opposition to Judge Thomas’ nomination for the Supreme Court. He noted that affirmative action has been a policy that has benefited the elite but not the masses in whose name they spoke. “Programs in private industry and academia have provided lucrative employment to minority elites as officials, consultants, researchers, and attorneys.”

It is my opinion a similar process occurs with some of the handicapped elite and those who, while not handicapped, are experts on our problems. There is always somebody who is willing to tell you what you should be doing. Me too! For example, you may have seen the front page article in the NAD publication, The Broadcaster, on the FDA and cochlear implants in children. It was a critique of the FDA’s decision to permit implantation of the device in children, written by the executive director of the NAD. As one who had spent the past five years of my career preparing submissions to the FDA, I felt he did not understand the FDA’s function. I was not impressed with his reasoning. He didn’t have it right. Philosophy really should not enter into an evaluation of safety or efficacy. The people making such decisions should have no interest in whether a deaf child must preserve his or her deaf heritage, whatever that may be. My membership in the NAD has lapsed.
Conversely, I have found there are many magnificent people out there who are willing to help. I don’t mean amateur and professional “do gooders”, just plain folk. Certainly there are many slobs and a fair number of bastards, but then there are days when I’m not the greatest, either. Some of them may try to undermine your confidence. Don’t listen. Others may try to stimulate you to do greater things. This is good, but should be your decision. Have you challenged you? Your conclusion as to what you will do is sure to contribute to your good health. Ulcers, intestinal difficulties and psychiatric problems, together with large medical bills, can be avoided.

My major concerns have been education and employment. Perhaps I am naive, but I believe you can be successful in adapting to deafness if you develop adequate skills and understand what is expected by employers. Even if you do not wish or need to work, just learning something new can fill a great void in your life. I believe in self-help. As I noted earlier, my life changed when I took charge of my own destiny. My motivation was reinforced when I came across this message by Whitney Young:

“There is a tendency, as natural as it is evil, to work not with the people who need you most, but with those who are most likely to be successful showcases for your agency. You like to pick winners, and that is understandable. People aren’t bets on a horse race or stocks on a market table. Winners win with or without you. But those persons who are defeated, who need the most intensive work and the most specialized skills, tend to fall by the wayside as agencies pursue successful statistics instead of meaningful service.”

In retrospect, I consider myself to be fortunate. The first half of my life provided me with a solid base for facing up to sudden deafness. When I was about 12 (1934), the depression was at its peak. Until I graduated from high school in 1939, I was able to find a variety of odd jobs to help out at home; delivering newspapers, caddying at two local golf courses, setting up pins at a bowling alley, and participating in the NYA (National Youth Administration) program at school. My first real job after high school graduation was as an elevator operator at a local hotel for the grand sum of $7.00 a week. I later became a bellman and received $4.50 a week plus tips. Some weeks were worse than others! Then I became a checkout clerk in one of the original supermarkets. Sixty hours a week for 12 bucks. Prices were not marked on the containers; you had to memorize the price of everything in stock. Prices changed on sale items each week, so it helped develop my memory.

The results caused me to look at other options. I decided that my father was correct in urging me to get an education. I started college but like others my age, I was drafted. While waiting to enter the Army, I worked for Squibb as an animal caretaker and laboratory technician. Before leaving for active duty with the Army I had chosen my future vocation; I would be a medical research scientist when I came home.

I have been blessed with relatives and friends who have helped me along the way. Among the early ones was a student nurse who took care of me after my first operation in 1942. She gave me a small sign that I still have: “When you reach the end of rope, tie a knot and hang on.” This single line has served me well for close to 50 years.

If I had had a crystal ball and could have seen into the future, I could not have planned it better. Of most importance, I met a young lady, an Army nurse, who became my bride in France. During the fifties I used to read a book to our kids, “The Little Engine That Could.” When I lost my hearing, I took the engine’s refrain, “I know I can, I know I can, I know I can,” as my own. What really made it work for me, however, was the echo my bride provided, “Of course you can, of course you can, of course you can!”
Some of the adjustments I have made in my life to face up to deafness, to live, and to work in the mainstream have been published and promoted by others after I had used them successfully. They do work! So dream a little. Chart your adventure to bring you to where you might want to be. Look for opportunities to fail. While motivation experts tell us “Desire + Decision + Drive + Determination = Success,” try to keep in mind what constitutes real success.

Personally, I like Ralph Waldo Emerson’s definition of success:

SUCCESS

“To laugh often and much, to win the respect of intelligent people and the affection of children; to earn the appreciation of honest critics and endure the betrayal of false friends; to appreciate beauty, to find the best in others; to leave the world a bit better, whether by a healthy child, a garden patch or a redeemed social condition: to know even one life has breathed easier because you have lived. This is to have succeeded. When you have decided what you want to do, climb aboard your personal butterfly and travel - you never now what you will find along the way.”
Coping with Recent Deafness: 
A Problem Solving Approach

Edna Shipley-Conner

Edna Shipley-Conner, Deafened Adult Coordinator for the Deaf Counseling, Advocacy, and Referral Agency (DCARA) developed and coordinates a program for people in Northern California who, like herself, became deaf or hard-of-hearing during adulthood. In this position that she has held for the past ten years, Ms. Shipley-Conner trains other people and agencies to establish deafened adult programs and writes a column in the DCARA NEWS that has been widely reprinted. Ms. Shipley-Conner was a Gallaudet University intern in continuing and community education in 1985 and has finished the course work for an M.S. in counseling. The following is an excerpt from her nearly completed Master's thesis. She is currently President of ALDA - East Bay in San Leandro, California and a frequent guest speaker at SHHH chapters in the greater San Francisco Bay Area.

When we become severely hearing impaired or deaf, the problems that we encounter often make us feel as if our ears have become huge; that we are nothing but "big ears that don't work." We need to be able to break up the big problem of deafness into smaller parts and learn to solve each of the parts. Shrinking the problem of hearing loss to a more manageable size and getting our ears back into proper proportion to our bodies can be accomplished by looking at how hearing functions and finding substitutes or replacements for each part.

Three Levels of Hearing

Hearing occurs at three levels: the symbolic level, the warning level, and the primitive level (Ramsdell, 1970). The first and most obvious level is symbolic; the part of hearing that is used to understand language. Loss of hearing interferes with the communication of language or conversations. Some aesthetic or inspirational experiences can be considered a part of this level, too. Music, the sounds of nature, and some religious rituals and services must be heard to be appreciated.

The second level of hearing is the warning level or the environmental level. Hearing is the one sense that enables a person to scan the environment from all directions at once. It works regardless of our focus of attention, the presence of light, and obstacles between a person and the source of sound, and it even works while we're sleeping. Hearing enables people to anticipate changes in the environment and warns of changes
that occur. The absence of unusual noises is reassurance that all is well (Luey & Per-
Lee, 1983).

The third level, the primitive level, is often the most unexpected and disturbing to people
who become completely deaf. Loss of the internal sounds that a person's body makes,
like teeth clicking and stomach growling is loss at the primitive level and creates a feeling
of not being alive (Baral, 1984). The deprivation is described as feeling that "nothing is
real", and as as a "world gone dead" (Johnstone, 1986). Jack Ashley (1970), a
deafened member of the British Parliament said that when the last little bit of his hearing
was lost, the world became an eerie place. These are examples of hearing loss at the
primitive level.

Substitutes for the Three Levels of Hearing

Now that we know the levels of hearing, let's focus on possible substitutes or
replacements. Substitution of the loss of symbolic level hearing is often accomplished
by learning sign language, speech (lip) reading, or other visual means of
communication. Since we have lost only the auditory part of our language, we are still
able to read. Using reading as a form of communication can be as simple as a pencil and
piece of paper or as complex as the latest technology. Making use of technology can
include real time captioning, TDDs, telephone relay systems, fax machines, television
decoders, computer mail, and more.

Replacement of the aesthetic part of the symbolic level is a little more difficult to do, but
it can be done. One deafened friend, who was an avid concert attender, now goes to the
opera more frequently (often with English subtitles) and to more ballet and dance
programs. She reads more poetry and finds that the rhythm of poetry fills some of the
gaps for the loss of music. Many deafened people become foreign film buffs because
they have subtitles. Also, movies are now being captioned for VCR or for special theater showings to deaf audiences. I often try to read the book version before going to
a movie or interpreted play.

While it is difficult to find replacements for chants, readings in unison, religious music,
and other religious rituals that are auditory, we can become inspired from being with
people with whom we share common beliefs and be creative about other ways to still
enjoy attendance at these functions. For example, stained glass windows have now
become an interest of mine. Some churches and temples have sign language interpreters
or special congregations for deaf people.

Substitutes for the warning level of hearing is accomplished by becoming more visual
and by making use of signaling systems, hearing dogs, mirrors, and similar items.
Check the conference exhibits for many of these devices or pick up a copy of Gallaudet
University's brochure titled Alerting and Communication Devices for Hearing-Impaired
People. These devices include flashing light and vibrating systems for the doorbell,
telephone, alarm clock, smoke alarm, a baby crying, and even the tea kettle whistling.

Using your eyes to replace your ears is what we do for language when we learn to lip
read and to sign. But we can also use our eyes as a substitute for the warning level by
observing what other drivers are doing, by scanning the area around us, and by noting
the looks that people have on their faces. When the earthquake hit in California in 1987,
I was stopped in my car at a stop sign. I thought that someone was bouncing my car
from behind and looked in the rear view mirror. The man's face in the car behind me
looked dazed and the man's face in the car in front of me looked dazed, and then I
followed their eyes to the light pole that was swaying back and forth, up and down.
Their expressions helped me to understand what was happening in the environment. I did not know that earthquakes produce sound since I had moved to California after becoming severely hard-of-hearing.

Mirrors are great; you can put a wide one in your car to help see more cars or people. You can put one on your desk to know when people are approaching you from behind. You can put a mirror in your hall way to know when a person is coming down the hall, or use one of the wide-angle mirrors on your front door to ensure that you have full view of who and how many people are outside. A mirror on the sun visor of the passenger side of the car will allow you to read the signs or lips of the person sitting behind you. However, this is not a good idea for the driver for obvious reasons. Be creative with your use of mirrors, and if you can think of another good one, please let me know.

Replacement of the third level of hearing is more difficult. In England, when a person becomes deaf, he or she is given a tactile device that will pick up sounds that vibrate against the wrist or abdomen. This device alleviates some of the trauma related to deprivation of sound and helps at the warning level to alert the person that someone is approaching or that a sound is occurring. It also assists with lip reading by cueing the deafened person about the length of the word being spoken and vocal inflection. Having been deaf for many years, one friend said that he now feels what happens inside his body rather than hears it. Others pay more attention to vibrations from machines, the floor, and perhaps even the “good vibes” we talked about in the 60s. I think of ALDAcons as a place where the good vibes of the 60s continue in abundance. We have our own way of replacing the loss of the primitive level of language with hellos, hugs, handshakes, smiles, and encouraging signs. We hope your world becomes more alive here at the convention, at least for a short time.

Development of Internal Head Noises

In addition to the loss of hearing, some people develop internal head noises. I saw one client several times after she unexpectedly became deaf. The Monday before Thanksgiving, she told me that she had awakened during the night thinking that her neighbor had the stereo on too loud. She kept hearing the same song over and over again. Later in the week, she was hospitalized for depression. I conferred with our case consultant, Dr. Larry Stewart who told me she was having auditory hallucinations, a phenomenon comparable to an amputee feeling their phantom limb itch or ache. Auditory hallucinations appear to be caused by a combination of auditory deprivation and depression. In my client’s case the hallucinations occurred just before she experienced her first holiday season as a deafened person.

A short time later another deafened client complained of a similar experience. I questioned her about whether the song was one she knew. It was a song that had been a favorite of her and her husband when they were dating. I suggested to her that just before she went to sleep, she think of a song she would like to hear the next day. In this manner, she learned to change the song in her head as well as to lower the volume. Since that time, I have asked other individuals who had recently become deaf if they heard music. Half of them responded with, “How did you know? I was not going to tell anyone. It is bad enough being deaf without people thinking I am crazy, too.” All were relieved to learn that, and to learn that their experiences were not abnormal. If anyone here experiences this repetitive song in their head, I would suggest that you try the above creative visualization technique. You may be able to change the song and it’s volume. Rest assured, you are not alone; other deafened people experience this phenomenon as well as some mentally healthy hearing people.
Common Ways To Describe Hearing Loss

In addition to knowing how the hearing process works and what we can do to replace hearing at each level, it also helps to know how hearing loss has been described and how it fits our own experiences. Hearing loss that occurs during adulthood has been described in four ways: 1) as a grief process, 2) as an accelerated and prolonged stress situation, 3) as a hearing vs. deaf identity crisis, and 4) as a competency crisis, both in terms of how deafened people view themselves and how others view deafened people. Sometimes there is also a fifth crisis that relates to career or employment.

Grief Process

Since Elizabeth Kübler-Ross first described the process of grief in her book, *On Death and Dying*, various people have described hearing loss as a grieving process. We go through the same stages of grief when we lose our hearing that we do when a person we love dies. It is important that we know those stages and how to identify them if we or others are stuck in one of the stages and need help. We have lost a vital part of ourselves, and our children, families, and close friends have also lost that part of us. When working with couples, I often say to the deafened person, “You have lost your hearing, and your spouse has lost your hearing.” Family members may experience a similar grieving process. My oldest daughter and I have a close, loving relationship. Yet when I began to have problems hearing and needed help with the telephone or shopping, she refused to help and became huffy. I was puzzled because this was so out of character for her. After attending a concert where she was singing with the university choir and the San Jose Symphony, some small misunderstanding occurred and she began to cry. Her tears were much too intense and long for such a little misunderstanding. I can’t even remember what it was. So I asked her what was really the matter. Her response was, “You can’t become deaf; you won’t hear music.” At that instant, I knew that my daughter was going through the grieving process for my hearing. I reassured her that my major reason for being at the concert was my love for her, not the music and that even though I would miss music, it was not one of my greatest losses. To this day, I think she still grieves for my loss of music. Be aware that your family may grieve for your hearing loss and allow them as well as you to go though the process without feeling guilty. Grief is a normal response to loss.

While grief is a common response to loss, what we grieve for and when we enter or re-enter the grieving process is a very individual experience. In talking with one deafened woman, she said that she had not gone through a grieving process. She had recently become profoundly deaf after having been hard of hearing for many years. Later, she remembered that 20 years ago she had suffered her initial loss following the birth of her daughter. The doctors told her she should never have another child and she had grieved for a long time afterwards. She had grieved for the children she could not have because of her hearing loss.

Another man that I know went through the classic symptoms of grief more than 20 years after he became deaf. He had been so busy earning a living and raising a family that he had not allowed himself time to grieve. When he retired, he had the time. Another person also did not grieve for 20 years, and yet another went through the initial grief process and then through it again 15-years later when she suffered a great disappointment related to her career.
Accelerated and Prolonged Stress Situation

Hearing loss is also described as an accelerated stress situation. Research was conducted to see if there was a common theme that caused all participants to feel stressed (Vernon, 1984). It was discovered that some people become stressed from trying to meet deadlines while others become creative with deadlines. Some people can tolerate work interruptions without feeling stressed and others become stressed by interruptions. The one thing that caused stress in all participants was communication breakdown. Hard-of-hearing and deafened individuals experience miscommunications and misunderstandings on a daily, even hourly basis. This adds another layer of stress to our already hectic lives. We need to learn how to plan and prioritize our schedules so that we can do the things that we really want most to do and to learn how to say “no” the other things. We also need to learn how to replenish and reward ourselves so that we have enough energy to do more of the things that we enjoy or that are our responsibilities.

Relaxation techniques can be a great help for this prolonged stress situation. Gallaudet University and SHHH developed a series of relaxation tapes that are open captioned for hard-of-hearing people and an additional tape that is signed and captioned for deaf people. These are available for purchase and can be used to determine the relaxation technique that works best for you. Most forms of exercise, from pleasant walks in the woods to working out at a gym are a tremendous help. Resources for learning relaxation and stress reduction techniques are available in libraries, hospital education programs, and in many popular magazines. They are also a regular part of the ALDA support group process.

While regular exercise and relaxation techniques lasting for 20 minutes or longer is optimal, you can do some relaxation exercises in less than a minute. The shoulder check is one. Push your shoulders back and down. Set up a routine to do this each time you get up from your desk or stop at a stop light while driving. Another quick and easy exercise is the quieting response. Make your face into a smile; the muscles don’t care if it is real or not. Breathe deeply in and out three times. On the last breath drop your jaw and exhale with your mouth opened. As you breathe out, try to imagine the breath going out of each of your pores. When it is not convenient to do the quieting response, going into a hallway or a bathroom, closing your eyes, and breathing deeply can do wonders for your ability to concentrate and to relieve or prevent feelings of stress. Being able to face hearing loss with a relaxed body and mind allows us to face other aspects of hearing loss with more energy and allows us to learn new skills that we need to survive as hearing-impaired people.

Identity Crisis: What Am I?

Another way that hearing loss is frequently described is as an identity crisis. As a deafened person, the dilemma becomes, “Am I hearing or am I deaf? Where do I belong? I can’t hear well enough to be comfortable with hearing people and I can’t sign well enough to be comfortable with Deaf people.” As we learn lipreading, sign language, and other language substitutes we will lessen the impact of the identity crisis. We can also learn more about Deaf people, Deaf culture, and the Deaf experience. I suggest that you attend the workshop this afternoon that addresses this topic. I also think that the establishment of ALDA and its growth give us a place to be “deafened”, to have an identity that is our own and that fits our experiences. By becoming active in ALDA we can help to expand this wonderful warm place where we can be who we truly are and make it a comfortable place for ourselves and others like us.
Identity – Competent Person

Learning to feel like competent individuals again is the other part of our identity crisis. As we finish our grieving process, learn new methods of communication, develop ties with ALDA, learn to use the good humor for which ALDA is well known, and form an identity with which we are comfortable, we will again act and be considered competent individuals. People who lose their hearing and learn to deal with it well are looked up to with respect by many people with whom they come in contact. As we act more competent, we will be viewed as more competent. In the meantime, remember the words of Dr. I. King Jordan, “Deaf people can do anything that hearing people can except hear.”

There was a wonderful poster that celebrated the International Year of the Disabled. The background was shiny black, with a beautiful red rose at the top and a single petal from the rose at the bottom. In white letters just above the petal the caption read, “Is it any less a rose?” Instead of thinking of yourself as a person with big ears that don’t work, try to hold in your mind the image of the rose. You are a fully functioning human being learning a new lifestyle and gaining a new identity. You are all beautiful roses. Thank you for letting me share some of my thoughts with you today.
Working it Through: Coping with Deafness and NF2 (Too)

Richard Skyer
Mary D. Skyer
Kathie Skyer Hering

Richard (Rick) Skyer holds a B.A. degree from Rochester Institute of Technology and an M.A. degree from Western Maryland University. Rick is currently employed as an analytical chromatography technician at Eastman Kodak Corporation. He is the chapter leader of ALDA Rochester and an ALDA advocate as well as a member of the founding National Board of ALDA. He is married to Solange Sevigne Skyer and has two children, Melissa, age ten and Michael, seven.

Mary D. Skyer holds a B.S. degree from Illinois State University and an M.S. degree from San Francisco State University as well as an ILS teaching certificate. Mary worked for several years as a rehabilitation teacher for deaf-blind people and is currently employed at the Independent Living Resource Center (ILRC) in San Francisco as a benefits counselor. She has been active in establishing ALDA chapters in Northern California and the Bay area.

Kathie Skyer Hering holds B.A. and M.A.T. degrees from the University of Illinois and an M.A. from Northern Illinois University. Kathie has worked in rehabilitation services for ten years and is a certified rehabilitation counselor. She is co-founder of ALDA, founding National Board member, current President of the Chicago chapter of ALDA and Board President of Will Grundy Center for Independent Living. Kathie is also a new member of the national board of N.F., Inc. She and her husband John Hering share their home with four Afghan hounds.

During the 1970s, while other families were coping with their reactions to leftist-leaning Commie-college students, our family was meeting at various audiology or ENT clinics trying to pinpoint the cause of our recent, profound hearing losses. Four out of five siblings became deaf between 1976 and 1978. All of us were in our twenties. Although it would seem that we would be able to cope together and to stay on the same path through our lives, this did not occur. Each of us had taken our own path in coping with our deafness and diagnosis of NF-2. We would like to share our story, our differences and similarities, and how our experiences as siblings gave us the survival skills that enabled each of us to cope with the impact of deafness and the recurrent surgeries in our lives.

This presentation will review the common threads in our lives, such as the age of onset and etiologies of our hearing losses, vocational/educational plans prior to
becoming deaf, and the information and options that helped us to determine our future goals. We would like to explain the communication choices and the lifestyle choices of two single females, one female married to a hearing man, and one male married to a congenitally deaf woman. We would like to share our experiences of “fence straddling” and of running off to join the deaf community through marriage, and how that affected deafened parent/hearing children family communication styles. We will discuss coping strategies that each of us has used to emotionally survive the interference in our lives by the resurfacing of various NF-2 tumors. We have all experienced facial paralysis that interferes with communication and have used different strategies to circumvent this. Our attitudes and opinions on the use of assistive devices and their usefulness will be covered. Finally, we would like to talk about our experiences with Vocational Rehabilitation service agencies from around the country.

Kathie Skyer

Being the oldest female in a sibling group of five, I have always felt compelled to take care of my younger brother and sisters. Our mother died when we were very young, ages three weeks to six years. Apparently, she had Neurofibromatosis Type 2 (NF-2) although we did not discover that until our own encounters with surgery twenty years later! During the early years of growing up only one of us experienced an unusual health problem and this was not attributed to a genetic disorder. To keep his family intact, my twenty-seven year old father remarried almost immediately to a divorced mother of three who did not have custody of her children. It was a marriage of convenience; she needed to prove that she was a good mother and he needed a mother for his children. After a few years of mothering us, she was able to obtain custody of her own children and the resultant sibling rivalry brought on by a his/her family increased the closeness between the five of us. Our stepmother died approximately ten years later from a hereditary heart condition complicated by alcoholism. My parents had relocated to a model community and there was no contact with my mother’s family for fifteen years. Ours was not a model family residing in the model community. Our stepmother was an alcoholic, our father was always working and we learned to rely on ourselves and to pursue independent lives. None of us remained at home long after high school graduation.

My primary goal after graduating from high school was to leave home and live independently, which is what I did. I wanted to attend college but realized that I didn’t have the money. I began a brief career as a mail carrier since working enabled me to live on my own. I enrolled in evening classes at the local community college. Eighteen months later I had become a full-time student with a part-time job, still on my own. My siblings were also entering this phase of their adult lives. We saw each other during holidays and spoke regularly on the telephone. One younger sister who was employed as a telephone information operator relocated to California.

My part time job was as a salesclerk where I regularly took orders over the telephone. When I began to notice that I could not hear well in my right ear, I used the other good ear instead of checking with a doctor. My co-workers made it a point to speak to me on the left side. At my brother’s graduation in 1974, we all had a good laugh altering our seating arrangements to accommodate our good ears.

That fall I had a very bad cold and flu and experienced an incident of vertigo. The family doctor I visited referred me to an ear specialist because there was evidence of
a mild hearing loss. This appointment was postponed for several months because I was a college student and had more important things to do. I was also working as a tour guide and began to experience distorted sounds as if people were speaking into a tunnel. I was terrified and finally made that appointment with the ear specialist. In those days, I didn’t know the difference between an audiologist and an ENT doctor; I just wanted someone to cure me. After being subjected to a number of tests a few weeks later, the ENT informed me that they suspected a tumor on my hearing nerve. At that point I wasn’t listening anymore. All I could think of was: tumor-cancer-death-my mother. The doctor suggested a special test that I could not afford. They recommended that I request this test from the ENT clinic at the university where I was a student and could obtain it free of charge. That was in May of 1975. All that summer I had the same hearing tests repeated that I had already paid for with the private ENT. I was never given the special x-ray that I had been referred for. I was told that a virus had damaged the hearing in my right ear. There ends the run-around.

The hearing in my right ear was gone by the time I started graduate school in the fall of 1975. During the third week of classes, my sister, the information operator, called to tell me she was in the hospital for tests to determine the cause of her sudden hearing loss. She said that the doctors at UCLA suspected a tumor on her hearing nerve. The doctors also suggested that the rest of us obtain CT scans to check for tumors as the cause for our hearing loss. In 1975 all of this medical talk, the language of professionals, words like ENT, tomogram, and CT scan frightened me. We had grown up believing that our mother died from a cancerous brain tumor. Actually, we believed that all brain tumors meant cancer. So, it was with a lot of reluctance that I contacted the neurosurgeon who had been recommended by the UCLA staff. After my first clinic appointment, I was scheduled for one week of tests in the hospital. This was the beginning of a three-year nightmare. I was placed in a room with a woman who was receiving radiation treatments for a cancerous brain tumor. She was very sick. And there I was: a twenty-five year old graduate student looking and feeling as healthy and as strong as Arnold Schwartzzenegger. I was petrified that week and constantly nauseated. Even routine hospital activities like taking blood every morning made me vomit. The nurses started giving me shots to prevent this nausea and all the time it was nothing physical. Later that week I was told my test results. I had an acoustic neuroma and was scheduled for surgery on Halloween. By Christmas of that year, both sisters, my brother and I had all had acoustic tumors removed. My sister who was the information operator was diagnosed with bilateral tumors and was deafened by January. That month she came to visit us. We learned how useful Magic Slates were and we communicated by writing back and forth. Events were happening so fast in our lives that we did not give much thought to learning a new way to communicate.

While we were recovering from these operations, my brother left Chicago to stay with friends. He suddenly became deaf and returned to Chicago to undergo exploratory surgery. My second sister was in the same hospital for a nerve graft procedure. My brother recovered quickly and was sent home. I said earlier that the fall of 1975 was the beginning of a three-year nightmare. During a nightmare when you start falling you expect to hit bottom. A week after the exploratory surgery, my brother decided to walk to church and then to visit me because it was close to my apartment. My dad called me and asked me to look out for my brother because it had started to snow, so I walked to the church. As I walked in the front door, my brother walked out the back door. I could see him ahead of me as we walked toward my apartment, but I couldn’t catch up to him or get his attention. I was
running and yelling at him to stop and wait for me. As he crossed the busy street to my apartment building I saw him slip and then fall. I watched the car hit him. He still had stitches in his head from his recent surgery. I was screaming and crying so loudly that my neighbors heard and called an ambulance. At the local hospital the medical staff decided to transfer him to the Chicago hospital where he had had the brain surgery. His arm was broken in two places, he had a deep cut over his eyebrow, and I felt that it was all my fault! My sister Mary was still in the hospital recovering from the nerve graft. When my dad and I arrived, we learned that Mary had to have surgery that night because of an infection. We left the hospital at eleven o’clock that night assured by a neurosurgeon that my brother would be fine because he had a “thick skull.” We already knew that.

My brother had suddenly and unpredictably become deaf. It was heartbreaking to watch him slide into depression and my attempts to cheer him were rightfully met with anger. He read books at family gatherings; writing him notes just frustrated him. None of us knew or were learning any sign language at that time. Neither my sister nor I were ready to talk about it (becoming deaf) happening to us too. My sister returned to her apartment, college, and to her classes. She changed her major from audiology to early childhood education. She had learned about NTID and sent my brother a catalog. He applied, was accepted, and enrolled the summer of 1976.

The surgeries were performed in the fall and winter of 1975-76. My life needed some stability, so that summer my significant other and I were married and bought a house. I returned to graduate school that fall in an attempt to resume living my life. I was determined to stay with my major, which was history education. I was not going to let it happen to me. Denial is a stage of grieving that is not as obvious to oneself at the time it is occurring as it is in retrospect. My father in law had a stroke six weeks after we were married and we spent the next six months concentrating on helping my husband’s parents cope. I was coping with my medical problems by avoiding them. Because I was a student for so long, my life seemed to follow the school calendar. By the fall of 1977 the hearing in my good ear was deteriorating. A CT scan revealed a small tumor. I dropped a class because the professor “whispered” when lecturing. Of course, it was not due to my hearing problem. I obtained a Bi-Cros hearing aid and continued to ignore the reality of my situation. Since my hearing continued to deteriorate, the aid wasn’t helpful for long.

I began to investigate career options. One of my college professors noticed that I was absent from two consecutive graduate seminars. We discussed these absences in his office. My sister was in the hospital at the time with serious complications following removal of an acoustic tumor. This discussion opened the floodgates; it was very hard to believe that I too would become deaf. This professor suggested that I meet with someone at a social service agency and also referred me for vocational rehabilitation services. I met with the agency director and began to learn about resources available to help me adjust to this traumatic change. Other incidents of tumor swelling, i.e. not being able to hear, forced me to seek help. I started meeting with a speech pathologist to learn to speechread, and my husband and I started taking a sign language class. Neither of us had any negative attitudes toward learning sign language; my husband is half-Italian and used gestures regularly while speaking. Even though it seemed as if I were taking positive steps toward adjustment, I was still willing to do anything to prevent the impending deafness. My neurosurgeon suggested I contact the medical staff at Massachusetts General Hospital in Boston regarding an experimental radiation treatment developed to shrink acoustic neuromas and therefore, preserve hearing. I was told by the
Mass General staff that this procedure would shrink my tumor and preserve my hearing for at least five years. I wanted to believe that, but I was deaf by August, six months after the treatment.

Meanwhile, I continued my search for career alternatives. The college placement office services were not at all prepared to assist me with this kind of transition. In fact, they treated me as if I were a nut case. So I did my own search to look for a career where hearing was not so important. I talked with the department chairperson of the deaf education program at the university I attended because I already possessed teacher certification and wanted to learn what other classes I needed to enter that program. I met with the school administrator of a local program for children with multiple disabilities. My audiologist and I had a discussion about the counseling program at Northern Illinois University (NIU). I asked the audiologist, "what do deaf people do?" and the response was that NIU had a program. We both agreed to seek further information.

Finally I met with the vocational rehabilitation (VR) counselor. No one will believe what I say next. I met a warm, caring person who happened to be assigned to my case. At that time I didn't know the process; I was just thrilled to have someone to talk with about my uncertain future. I was referred for psychological testing to the person who would eventually become my counselor. This counselor helped me come to terms with what was happening to me. We had two appointments. I missed the third one because by then I was in the hospital for the removal of a second acoustic neuroma.

A few weeks after recovery, my VR counselor and I made a plan. I would attend graduate school the following fall, but first I had to learn sign language well enough to use an interpreter, increase my speechreading skills, and meet regularly with the counseling psychologist to facilitate adjustment. The counselor didn't know sign language or much about deafness rehabilitation. For that matter, neither did I. The counselor did, however, know about the grieving process and about self-esteem needs. As I talked, the counselor listened and wrote more questions. I attended sign language tutoring sessions two to three times weekly. During the evenings, I would teach my husband the new signs that I learned. I still had to take my comprehensive exams to obtain my M.A. degree in History.

The year between August 1978 and August 1979 zoomed by. One year after becoming deaf I was enrolled in another graduate school program and living on campus. The resources available to me were a major factor in developing my coping strategies. I was enrolled in a graduate program, I lived in a major metropolitan area, and I had the determination to seek information that would help smooth my transition from being a hearing person to being a deafened person. I learned about the kinds of challenges that I would be confronted by. I had also closely observed various situations as they happened to my siblings. The sister who attended classes at California State University at Northridge (CSUN) participated in a research project by Carolyn Hunter. Hunter's research was summarized in her M.A. thesis A Pilot Study of Late Deafened Adults, which I read before I became deaf. At that time I thought some of the statements sounded like paranoia, and other statements pertaining to having friends drift away or differences between the hearing world and the deaf world seemed to me to be off-the-wall and certainly did not apply to my experiences at the time. As I became progressively more deafened, I realized that Hunter's comments were right on the mark. I tried to keep a journal and in 1977 wrote, "It's funny that Carolyn (Hunter) would state that deafness makes you avoid making new friends. I have slipped into that too."
Hunter was a counselor at CSUN and served as a role model for me. I never met or corresponded with her personally. I did complete the research questionnaire that was the basis for her thesis. However, because I was not yet deaf my responses were excluded. I learned to bluff without identifying it as such. In another journal entry I wrote: "How to respond is just as important as knowing what was said. If the response is incorrect, they will know you are deaf." Learning to live with deafness for me is a continuous process. Knowing that I told myself to bluff in 1978 makes me laugh now. A recurrent issue in my life has been that of independence versus dependence. It was one of the motivations for completing graduate school and obtaining employment as a rehabilitation professional. It has proven to be a major concern of mine in terms of my ability to cope with NF-2 as well.

I began my professional career in 1981, but employment was not enough for me. I became actively involved in various professional groups. I had encountered a few other late deafened adults in my work and was saddened by the lack of services that they had received and the lack of understanding of their needs by service providers. These people were just like me, but they were miserable and I was not. This made me wonder whether my own experiences were unique or whether others' experiences were caused by ignorant VR counselors. Because of my leadership role, I became familiar with all of the various metro area services for people who are deaf. However, none were prepared to assist a late deafened adult. A counselor friend called and asked me if I would be willing to meet another late deafened adult. Many late deafened adults are very isolated and never have an opportunity to meet others like themselves. After this meeting, my friend and I discussed the need for a support group. My friend arranged self-help group leader training for members of Self Help for the Hard of Hearing and me. The intent of this leader training was to teach us how to set up self-help groups. I was already trained as a counselor and was somewhat reluctant to recognize the benefits of self-help rap groups, especially after participating in a group counseling experience, which is different than self-help.

As I said before, I took the leadership training program with members of Self Help for Hard of Hearing people. I was the only deafened person in the group and I required a sign language interpreter. Because I am proud of my sign skills, I sign whenever I speak. This group of people asked me not to use sign language. It obviously embarrassed them and I learned that using sign was taboo for some hard-of-hearing people. Their objections to my communication needs emphasized the separation between deafened and hard of hearing people. When I started a self-help group in October, all of the service provider contacts said the group was needed. I knew there was a need, but people were slow to participate. In April of 1986, my life jumped in my face. A routine CT scan discovered a life threatening tumor, that had to be removed immediately. I was devastated by this. I was angry!! How unfair; I had coped well with the deafness and now was being thrown a curve ball. I had to let go of my future dreams and plans, and I had to let go of my plans to start a family. My anger was enormous. Because there were medical complications after surgery, I could not return to lead the group and it disbanded. However, this group later developed into the Association of Late Deafened Adults (ALDA).

I don't think in terms of numbers. The reason I am giving numbers now is simply to demonstrate that you can cope with NF-2. I have had more than a dozen major medical procedures since 1984, all related to NF-2. Consequently, I have made it my business to learn as much as I can about deafness and its impact on people's lives; acoustic neuroma surgery and its impact of people's lives, and NF-2 and its
impact on our lives. I have also become involved in various groups that are related to the self-help movement as well as those groups involved in advocating for the rights of people with disabilities. I believe knowledge is power and a means of exerting control. Understanding the process of what is happening to me is a way for me to maintain some kind of control in an uncontrollable situation. It's a little like driving; we all have contingency plans and make sure our cars are safe to minimize risk. I don't dwell on what could go wrong; I look for the end results. I can't live in the future as some people do so I have learned to live in the present.

I have said that for me, knowledge, a sense of humor, faith, and optimism keep my life in perspective. I try to remember that the tide always comes back. I have received enormous emotional support from my husband who has a sense of humor that is as absurd as mine. Mary said earlier that she used to think that the telephone was attached to my ear. Well, my husband used to think that our phone bills would be insignificant after I became deaf. He didn't know about TDDs or of the emergence of relay services. We have been together 21 years now, and I am sure that he learned sign language so that he could win an argument every now and then. Our relationship continues to evolve; it is not static. It changes as do the challenges of this progressive disorder. Wars are won one battle at a time. Thank you.

Rick Skyer

I am the baby, but a very big 200+ pound baby! From what Kathie said, you know that we had a bad history. We didn't know about the genetic problems, but I did see some pictures of my mother and I was very surprised and frightened. I felt guilty about being frightened of my mother. I still feel guilty, but now all of us have that kind of facial disfigurement. It is not as startling to witness now as it was when I was a six year-old boy. When I first saw family pictures with all of us nestled together on the couch with our terminally sick mother, it scared me quite badly. Later I was told that the maternal half of our family thought that I had caused her death; that I had killed our mother! That was a very heavy burden for a young child to bear. It was not true, but at the time there was no proof and it was hard to deal with the accusations. That was our bad start in life, although it did get better. In high school I became a star; a sports hero of sorts. I was a singer in a highly acclaimed choral group. I hadn't had any problems yet, but by the end of high school they started to become more apparent. My balance was terrible. I nearly drowned two times despite my experience on the swim team and my excellent movements in the water. Kathie said that it was during this time that we learned about the tumors and became deaf. In reality, a lot of other things happened, too. Some of them involved grieving, but also many good things occurred, and these are what I wish to share with you. There have been many effects resulting from this disease that are both positive and not so positive. I can choose to see my life as a tragic event, or I can see it in a more positive light. It all depends on how I look at it. There has been only one way for me to look at my life and this is from an enlightened perspective.

I went to school at the University of Illinois, Chicago Circle campus for a few years and then transferred to the Urbana campus with hopes of entering medical school. That all changed after the tumors were discovered and I found out that they required surgery. I had to accommodate for this turn of events. As Kathie candidly remarked, I ran away to the Deaf community. Actually, I had just moved to New York and started school at the National Technical Institute for the Deaf (NTID). I had also started to learn sign language and about Deaf culture. In short, I wanted to
continue with my education in as much the same way as it had started. It was
necessary for me to change my majors to biology and chemistry, but that was a
trivial thing since all fields of medicine required that information anyway. I was at
a major crossroads in my life and the path I chose was a step in the right direction.
When I went to NTID it was a wonderful time to vent some of my frustration, but it
was also extremely difficult to make the social transition. Two people played key
roles in my transition; one was a priest who knew sign language and the other was
a counselor who later became my wife. But let’s get this straight: she was not my
personal counselor!

While I’m on the topic of school, let me bring up the issue of facial paralysis and
it’s effect on socialization within the Deaf community. It would be unrealistic to
think that our personalities could shine through despite our hindrances. You would
think that we could still be ourselves, and basically we are. But you must also
remember how critically important facial expressions and body movements are to
communication in a Deaf society. That can’t be emphasized enough and yet there is
nothing that we can do about our paralyses. It is a strike against us, and trying to
naturally use our vocal inflections to change the tone of a conversation doesn’t
work. It is obvious that deaf and hearing-impaired people don’t hear, but we have
to be constantly conscious of tone; it is natural to tease with your voice. It is second
nature for most of us in the family to chide others in a sarcastic, playful way. Deaf
people in general cannot appreciate this as it is intended; it is taken as an affront.
Given that our voices are misunderstood to begin with and then add to that the fact
that there are no smiles to go along with the teasing, it is perceived as a compound
assault, even though it was meant to be funny and to show ourselves as good
hearted people. In this light, it is pretty clear to see that before we even come to bat
we have two strikes against us. However, many a home run has been hit on a full
count and we have done this despite the set-backs of deafness and facial limitations.

I’d like to get away from this analogy and on to more serious considerations. The
topic of lost friends comes to mind. We all have them. It is not typical of people
who are only deafened, however. People forget about this all of the time. We
sometimes want to wallow in self pity, but realistically no one has the same
friendships that they did in the past. It is part of growing up, and although this
stage was hastened for us, it has not been as traumatic as you might think.

I’m going to move on to communication channels and schemes. This glowing
thing here in my pocket is a vibrotactile device. It changes electrical energy into
vibrational energy that you can feel. It is confusing, but you learn to sort sounds
out. Still, it is not a panacea for sound, or a replacement for your ears, or even a
hearing aid. It does help considerably, though, and all the little things that might
make communication easier for us are important to try. That was easy to say, but it
took me 15 years to realize just how much the vibrotactile device can do for me. It
alerts me to my own voice, to the environment, and is especially helpful in one-to-
one conversations. It is true that most of the time I am not in a one-to-one
communication setting, but the devices is so helpful when I am that it is worth
lugging around. I tried one for the first time back in 1976 at NTID. At that time
there was only one channel. I was reluctant to try it or to try anything that would
reinforce my thoughts of deafness. I had just lost my hearing and was being
defiant. In retrospect, I was very ignorant. I wanted nothing to do with this
vibrating thing. I had all kinds of excuses. I couldn’t afford the batteries, I couldn’t
decipher that garbage, etc. I was in complete denial. Ten years later, when my
defiance had waned and the reality of deafness had set in, I tried it again using the
new two channel device and found that it was helpful! I used it constantly even

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though I had a wire running down my arm. The latest model, a seven channel
device is what I have now and it is what you see glowing ceaselessly in my pocket.
It is helpful; not a cure or a replacement for hearing, but then nothing is wrong with
me trying to ease my way. With two strikes against me already this is a way for me
to at least stay at bat and wait for the perfect pitch so that I can hit a home-run.

These next topics of marriage and family are very delicate ones for all of us. I was
able to get though school, meet a few nice ladies and stick with one. The last lady
is the source of my happiness, my dreams and my children. It is hard for me to
consider what would have happened or what could have happened had I not
become deaf. Although were all have a lot of fantasies, this reality is what I have
accepted and I have not looked back. It is an attitude that I had to take if I wanted to
move on. Like I have said before, it is the way we look at life that is important.
That is what has worked for me, and hopefully you can relate some of these ideas
to your own situation.

With our mother, there was little information about the genetics of NF-2. Research
had progressed somewhat in the years prior to our decision to have children. At the
time, we knew that the possibility of deafness was 50:50. My wife was born and
raised deaf, and has succeeded far beyond anyone's expectations, including her
own. It was solely due to her efforts and the way she chose to view her plight. It
would have been easy to see it from another perspective; to give up and sit back,
not unlike that option afforded to deafened people. Each of us here has changed
our own views of life and made them positive. There are those people who do not
have a positive outlook. Admittedly, it is difficult to do at times, but we need to try
to be positive. Anyway, with my wife's ability to manage her deafness and my
own adaptability, we felt that deafness was no big deal. There was nothing that we
couldn't handle together. We made the decision to have children only after we
sought genetic counseling and openly discussed the possible consequences. There
was no knowledge of spinal injury ramifications back then, although it worries us
now. Our children are periodically tested with an MRI and BERA audiometry. It is
not shaping our lives, and should not shape anyone's life because there are many
alternatives. I would like to thank you for listening and for sharing with us some of
our experiences. Hopefully this catharsis of emotions can be beneficial to all of
you.

Mary Skye:

Kathie asked me some time ago how we manage to cope with becoming deaf and
having NF-2, as well? I just laughed and said, "We get lots of practice!" The more
I think about it, that's a pretty accurate assessment. One thing that I did not want to
do today was to get into family systems theories. I don't want to get into medical
terminology or technology either. Kathie explained that we come from a
nonsupportive home environment. Rick spoke of some of our experiences. I
would like to touch on our personalities, because we are very different by nature.
No doubt most of you met Rick and Kathie long before you met me. Both are
extroverts whereas I am introverted; the shy, quiet one. Kathie was always very
popular and always on the phone. She's like a little bird chattering away her happy
little songs. We had this 20-foot phone cord and she would walk around with it,
strangling us in the process. Rick was always the all-American kid with all the girls
in school drooling after him. I understand that his son is pretty much the same
way; this little guy has his teachers wrapped around his little finger already! Even
now these two can go into a room full of strangers and strike up friendships right
off the bat. I am the timid one who takes a while to circulate. My timidity is
directly related to our stepmother’s ridiculing and her volatile disposition. I loved to sing, but I didn’t want anyone to hear me! A few years ago my sister-in-law remarked that Rick had told her once that I had a beautiful voice. Had I known anyone was listening I would have stopped altogether. I have never found a replacement for my guitar and singing. I can now sit in the same room with a guitar without crying.

I said we had extensive practice coping with difficult situations. Let me give you an example. Rick had a pet grasshopper that became sick. It was one of those big green things that leaked brown stuff all over the place. Oh, but he loved his bug. It stopped eating and Rick tried to keep it alive even after it was obvious that the grasshopper was dying. At first, Rick denied that it was sick at all. Then, he figured that if he did this or that, the bug would live. It died. Rick was furious! We found a little match box and lined it with cotton balls to make sure the bug was comfortable. We had a funeral and all of us said a few words about our relationship with this bug. We made a cross out of Popsicle sticks. Rick probably remembers the grasshopper’s name to this day! My point is that we helped each other work through things. We did not get support from our parents but we gave it to each other when we could. We still do that.

My situation was a bit different from Rick’s and Kathie’s. I had my left eye removed when I was five years old. That was probably the first symptom of NF-2 in our generation. It was not until we were in our early twenties that the other symptoms surfaced. I was a student then and spent a good deal of time bouncing from one doctor to another. One gave me a lecture on not trying to solve the world’s problems by myself. He gave me tranquilizers and told me that it was all in my head. I would have excruciating headaches and nausea, and the doctors would say, “Well, we can’t find anything wrong with you but you look sick!” No one ever connected our mother’s death with our experiences. Our father denies that she had any hearing loss. We were all having the same problems at pretty much the same time. Finally, it all fit together. Rick and Kathie had surgery before I did, and because of that, I was not so afraid. An acoustic neuroma had been my only diagnosis, so I did not believe that I would become deaf up until the night before my very first surgery. However, the night before surgery, the surgeon let me know that there was a suspicious area on the right side. I was already deaf in one ear and blind in one eye. I was running out of body parts! I knew that I would become deaf soon.

After becoming deaf, I wanted to finish my B.S. degree. At the time, I worked part-time jobs. I was miserable. I did not know what I wanted to do. I did not know what I could do. Everything looked the same. I was depressed, I got help, but not from the doctor. In fact the doctor made it worse. Eventually, I made the decision to visit NTID. It was a very important visit. It was then that I realized what I wanted to do, and it wasn’t following in Rick’s footsteps. The visit to NTID taught me that I wanted to work with people. Also, something else happened. I started laughing again. I had picked up a copy of my sister-in-law’s book about Garfield the Cat. I don’t know how to describe it; a damn broke. I laughed so hard my sides hurt. It just triggered something in me.

I said earlier that I did not want to discuss family systems theories or medical issues. We are just sharing our own experience as individuals and not as professionals. I do not want to make it sound like we are Supercooper or even Super-Family. I suspect that our home life did indeed make us more resilient and
tenacious in some ways. For me, I found my sense of humor gets me through the surgical ordeals and periods of readjustment.

One last thought: Remember I said that I was always the quiet one and I had visited Rick and Sally at NTID? Well Rick complained that I was not talking enough or being friendly enough. I went into the library at NTID and struck up a conversation with one of the students. I was kicked out the library for talking too much.
Section Four:

Family Relations
Structural and Communications Issues of Families With Members Who Are Deaf

Randall R. Myers
Shirley Shultz Myers

Randall R. Myers, LSW has been the Editor of the CODA newsletter since 1989 and a member of the organization since 1985. He has presented extensively regarding the hearing children of deaf parents experience and the CODA organization. Both of his parents are from New York and several members of his extended family are deaf. Since 1989, he has worked in the Illinois Department of Mental Health and Developmental Disabilities as the Statewide Coordinator of Deaf Services.

Shirley Shultz Myers, Ph.D. is an Associate Professor at Gallaudet University where she has taught for the past 12 years. Her parents reside in York, Pennsylvania and several of her extended family members are deaf. She has been a member of CODA since 1985.

Mr. Myers

My wife and I are very pleased to have the opportunity to present some of our observations and experiences about the structure and communication issues in families with deaf members. Both of our parents are profoundly deaf, so we share some of the issues of concern to hearing children of deaf parents with particular attention to late deafened parents.

Let me start with an explanation of why we decided to do this particular workshop. There are four reasons:

1. Your interest
The article in the ALDA News, Ask Dr. Deaf, focused mainly on the signing vs. non-signing issue. The need to focus on the issue of how family members communicate is introduced into the family structure when one member becomes deaf. This issue involves gaining recognition that new methods and modes of communicating are necessary for all family members. All family members need to take time to explain how they’ve always communicated, how they feel about these methods of communicating, and new communication requirements in the family.

Orlans (1985) suggested that the following factors as influencing the family’s stability when late deafness occurs in the family: 1) the severity of the hearing loss, 2) the characteristics of the individual(s), 3) the family’s integrity, and 4) the family’s stage of
the life cycle, meaning the age of the children with regard to the stage of individuation from the family and the levels of support inside and outside the family.


2. Questions about hearing children of deaf parents' signing skills
It is strange, and perhaps unexplainable, that some hearing children of deaf parents sign and some don't. Why? We don't know for certain, but we will be proposing some ideas that go beyond the obvious. For example, a child might recognize on an emotional level that his or her parents are less perfect in some very obvious way. We all know that parents are not perfect, but children like to think they are.

3. Facilitating communication
Hearing children of deaf parents are often affected by the pressures of facilitating communication between family members and the outside world, even if they are not directly asked to interpret. In a sense, it might be knowing, or hearing, more than other members which can have a powerful emotional impact such as anger, resentment, or disappointment. This feeling of needing to interpret might become more intense and/or obvious if the parents are less able to communicate directly with hearing people themselves either through speech or sign language. However, with a parent or parents who can speak and who are profoundly deaf because they are late deafened, the child may experience a great deal of confusion about what the parent is able to do and not do.

4. Building bridges
Finally, we're interested in building bridges of common experience between the CODA and ALDA organizations. Your kids became hearing children of deaf parents when you became deaf. Your kids will be hearing children of deaf parents if you have any children in the future! Some of us who are hearing children of deaf parents and who have late deafened parents come to CODA Conferences. In addition, CODA, for the first time, invited late deafened hearing children of deaf parents to their Conference Retreat and provided interpreter services throughout the event. The experience of those who became involved for the first time with other hearing children of deaf parents was momentous and marvelous for everyone involved.

Our CODA organization was founded in California in 1983 and focuses on the needs of hearing children of deaf parents. We have yearly conferences and have structured them in the form of self-help retreats. For us it is an invigorating opportunity to get to know ourselves better among those who know us best; our hearing children of deaf parent peers. For hearing children of deaf parents around the world, these retreat opportunities have been a Godsend.

The Structural Approach

The field of mental health services for people who are deaf or hard-of-hearing owes a lot to Dr. Michael Harvey, a Massachusetts psychologist who proposed that we analyze the dynamics of deafness in families through a structural approach. His recently published book (1989) *Psychotherapy with Deaf and Hard-of-Hearing Persons: A Systemic Model*, has chapters on both late deafened adults and hearing children of deaf parents. Although we all live in structures like schools, governments, and agencies, one basic structure for most of us is our family. There is a structure in a family: mother, father, sons daughters. Each of these individuals has his or her own role in determining how the family operates and communicates. There's also the extended family; made up of grandparents, cousins, aunts and uncles, brothers and sisters who may also live in the home. Dr. Harvey
maintains that when deafness is introduced into a family there is, in essence, a snowball or ripple effect that causes all members of the family to eventually be affected by it in one way or another. Even people or groups outside of the immediate family, including the extended family, helping professionals, school personnel, and co-workers can be affected. The equilibrium of the system gets thrown off balance. Even though a family may maintain stability after a member is born or becomes deaf, its members have still been affected in many ways. The family should reach for some place of support where concerns and feelings might be aired. In mental health situations, when we work with families that are dysfunctional, we are essentially working with family systems that have gone awry. It is wise for the family not to underestimate the need to explore feelings, especially the more difficult ones, even in families that seem the most stable. If you have had this opportunity with your family, or perhaps individually through the ALDA chapter in your area, you probably have benefitted from it and so has your family.

Now, I want to show you a chart that illustrates the family structure of families with deaf members and hearing children of deaf parents.

This chart illustrates some of the factors that enter into the system of families with members who are deaf and hearing. It can also be used with families who are late deafened. On the top, we have the extended family. The extended family includes the mother’s parents and the father’s parents. In the middle, we have the mother and the father, and on the bottom, we have the hearing children. You can see that they are all connected. Moreover, the extended family members are connected to the children. Most extended family members are hearing, the parents are deaf, and the children hearing, so the deaf parents are, in essence, “sandwiched” between their hearing children and parents. When we assess the structural impact of the deafness, we need to know about the extended family: Are the grandparents deaf or hearing? What are there are attitudes? Do they sign? Do they sign to their deaf children? Are they protective of their deaf children? Second, we look at the deaf parents and examine their communication modes, languages and attitudes between them and their respective parents. Relevant questions include whether the deaf parents depend on their hearing parents, whether the deaf parents are proud to be deaf or not, what the deaf parents’ relationship is with hearing people, whether they like hearing people, and what their attitudes are towards hearing people. These issues have a strong impact on the hearing children. Third, we need to look at the communication system of the hearing children: How do they communicate with their parents? Do they sign with their parents? How do they manage their parents’ deafness? Have they accepted the fact that their parents are deaf? Do the parents depend on the children in some ways? We suggest that the communication system of the parents and extended families will influence the children’s communication abilities and attitudes. Finally, we need to know the relationship between the hearing children of deaf parents with the hearing extended family members, such as grandparents. The chart illustrates only some of the factors that might enter into the family system with deaf and hearing members. Maybe you can think of some other factors and whether or not and how these issues affect your family. Consistent with Harvey’s structural approach is the belief that it is important to recognize and to accommodate pre-existing ways of communicating before any restructuring or the change of family communication can occur. In other words, it’s important to acknowledge how the family communicates and used to communicate. We cannot ignore how the family used to communicate. Each family member needs to present their methods of communication, and, perhaps, why those methods may not be effective any longer. The family members can then discuss preferred communication modes that allow for access into conversations.
EXTENDED FAMILY
Mother and Father's
Parents, Aunts, Uncles,
Cousins, and other relatives

Are extended family members:
1) deaf or hearing?
2) signers or non-signers?
3) accepting of signing?
4) protective?
5) accepting of deafness (attitude)?

What are the parents':
1) communication modes with parents?
2) communication fluencies with parents?
3) dependence on parents?
4) self-esteem?
5) relationship with hearing people?
6) attitudes about hearing people?

DEAF PARENTS
Mother
Father

What is the hearing child's:
1) birth order?
2) signing ability?
3) communication preference with parents?
4) management and reconciliation of deaf and hearing communities?

HEARING CHILDREN
Sons
Daughters

Hearing Children of Deaf Parents
Relationships in the Extended Family:
Structural and Communication Issues
(1992 by Randall R. Myers, LSW)
Now Dr. Shultz Myers will continue our talk using this chart to discuss additional family structures and variables that affect communication. She will also discuss the structure of families that have members who are late deafened. Finally, she will continue to explore some of the inner life of hearing children of deaf parents; some of it is emotionally sensitive material that may interest you. We would like to spend the rest of the time answering questions from you.

Dr. Shultz Myers

Mr. Myers talked in general terms about the structure of the family when there is a deaf member. I will focus on the hearing child because that is what I understand best. You can tell me the late deafened experience, but I am trying to share our experience. Maybe there are some late deafened people here who are also hearing children of deaf parents. There is great diversity of experience among hearing children. I will try to start with what is common.

The nature of the hearing children of deaf parent experience involves a sense of living in the interface of two worlds, deaf and hearing. Such circumstances provide fertile soil for cultural and personal enrichment. Potential also exists for emotional conflicts, some minor and others quite intense.

Do you as late deafened adults feel that you do not or will not have the same situations affect your children as those that affect hearing children of other deaf parents? After all, you were once hearing, just like your children. Let me ask some other questions. When you became deaf, did you have any conflicts or adjustments to make? Did you become aware of “differentness” that you did not feel before becoming deaf, a “differentness” that sets you apart from the hearing world to any degree? Whether you answer yes or no to these questions, we suggest that your children potentially face conflicts and a sense of “differentness.” Even if your adjustments were minor nuisances to you, it would be wise not to assume your children’s feelings are the same and to overlook any possible hidden feelings, that even the children themselves may not be aware of. Assume that in one way or another, your children will understand the basic hearing children of deaf parent experience of interfacing between deaf people and hearing people.

If you didn’t have something unique about your experience, you’d just be part of the majority Deaf community, without a need for ALDA. But you come together because all of you have experienced first-hand what life in both worlds is like, and because, even now, you may feel on the edge of both worlds. The good news for late deafened adults is that, because of your experience, you might understand more than other deaf parents the experience of the hearing child of deaf parents of living in two worlds. Amazingly, we have some hearing children of deaf parents who are also late deafened, and they are in the best position to teach all of us!

Space allows only brief mention of how we might begin to look at the complex mix of emotions belonging to hearing children of deaf parents. Most of us are aware of the need not to abuse hearing children as interpreters. In addition, a number of us know open, clear communication is paramount for building strong, healthy bonds between parent and child. However, the emotions resulting from numerous factors listed below are a bit harder to understand.

Emotions are rational and irrational. Emotions are also negative and positive. An example of positive (and rational) feelings of a hearing child of deaf parents is happiness that the Deaf community has gained respect in the larger society as a cultural and linguistic
minority. As a result, we hearing children of deaf parents can take pride in our participation in this community. Yet we are also aware of ongoing stigmatization of the Deaf community by hearing people and, conversely, a rejection of hearing people by deaf people. These difficult situations arouse conflicting, painful emotions. It is most difficult to talk about some of these negative feelings for various reasons. One reason is because we have internalized a kind of taboo against in any way making deaf people “look bad” to hearing people. Another reason is that, when we identify with our deaf parents and suffer from hearing peoples’ prejudices or condescension, we also suffer guilt because we are also hearing and too much guilt can undermine self-esteem. We feel it is valuable to talk about such feelings, not to reinforce a pathological view, but to deal honestly with the pain as well as the love in family life in order to be whole, healthy people. Individual personalities of hearing children of deaf parents influence how each one reacts to similar experiences; we only hope to sensitize you to possibly intense and sometimes upsetting feelings. We believe releasing the hold of thorny emotions frees the family to enjoy the bloom of family love all the more. Dr. Deaf is right: “(The) fact that you are deaf will not have irreversible repercussions on the mental health of your children. How you handle that fact will.”

The Hearing Child of Deaf Parents Experience Within Families With Late Deafened Members: Factors

The factors influencing families with deaf members are numerous. In addition to those factors described within the structural family model (see previous chart), the following are other important factors that need to be considered:

General Sociological and Family Systems Factors

1. education (formal and informal)
2. income
3. race, sex, ethnic and/or religious background, and other disabilities, or physical challenges
4. family systems
   a. dysfunctional disadvantages (alcoholism, incest, physical, sexual, and emotional abuse, toxic interrelations not limited to any one group of people)
   b. learned parenting skills across generations
   c. relationship boundaries: rigid, disengaged, enmeshed, healthy
   d. patterns of communicating or not communicating feelings

Note: All of the sociological factors have psychological impact; in addition, the way a person reacts to such factors is influenced by personality.

Late Deafened Factors

Self:
1. age when person became deaf
2. late deafened person’s attitude toward own deafness and adjustment; degree of resolution of internal conflicts; self-esteem; self-concept
3. late deafened person’s relationship to/attitude toward hearing and deaf communities
4. work or career change as a result of deafness

Spouse:
1. married before or after becoming deaf (if before, what is the impact on the marriage?)
2. spouse hearing or deaf

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a. if hearing: relation, if any, of hearing person to deaf people other than late deafened person spouse
b. if deaf: Deaf community member; late deafened person; born deaf; hard-of-hearing, and so on.

Extended Family:
1. existence of any deaf relatives of the late deafened adult or of the spouse
2. relationships
   a. late deafened person’s relationship to late deafened person’s own parents
   b. late deafened person’s relationship to spouse’s parents
   c. spouse’s relationship with spouse’s own parents
   d. spouse’s relationship with late deafened person’s parents
3. communication modes used in each relationship
4. attitudes of late deafened person, spouse, and both sets parents toward deaf and hearing communities
5. role of grandparents in grandchildren’s upbringing
6. in both sets of grandparents, resolution of feelings about deafness
   (includes protectiveness issues, grieving, guilt, and others)

Children:
1. children born before or after spouse became deaf: start of hearing child experience
   a. if before, this factor links to question of communication mode and adaptation issues
   b. also before or after, the mode of communication each parent uses with the children and the mode that the children use with the parent
2. children’s relationship to deaf and hearing communities
3. dealing with stigmatization, anger, guilt about anger, and the like
4. identity confusion
5. role reversal; risk of parentification of children in functioning with hearing world and in emotional responsibilities

We ask that you to keep all of these factors in mind, particularly those most important to your situation, as we focus on the last category, young hearing children of deaf parents still living at home. We can only sketch some of the more subtle, potentially emotional development issues. Develop and apply what fits you and your children.

Here are three basic issues:

1. The deaf parent’s self-concept as a deafened adult affects the young child’s perception of the parent as well as his or her own self-concept. The child must also overcome hearing people’s possible stigmatization.

If the parent communicates some devaluation of him or herself to the the child, or the child has not come to terms with the parent as deafened person and internalizes some societal devaluation, the child may react in various ways: The child may become ashamed of you; be angry at you; be afraid to express anger for fear of further damaging your self-esteem; reject sign language and deaf people in general; overcompensate by trying to parent or nurture the parent to develop positive self-esteem; try to be perfect to gain respect in what is perceived as a hostile hearing world; compensate or react against negative feelings with caring, protective or supportive behavior; and accept an interpreting, caretaker role that is rewarded by parental esteem (good child, good signer) and by power over parents.
2. If a positive identity as a deaf person includes a negative view of hearing people, then the hearing child's self-esteem may be undermined in one of two ways:

a. The deaf parent complains about discrimination and says derogatory things about hearing people; the parent knows the frustration is momentary or limited to certain people but the child may assume guilt as a hearing person.

As a result, the child may blame him or herself, feel guilty, or worry about being a rotten hearing person; feel an overwhelming need to fix things; have difficulty finding his or her place in the hearing world, and yet not feel secure in the deaf community either; or turn to hearing grandparents or a spouse to repair a devalued sense of themselves as hearing people.

b. The parent affirms other deaf people's wishes to have deaf children. There is another side to this seemingly positive position for deaf people to take: It could make a hearing child of deaf parent feel rejected or second-best, just as some deaf people complain their hearing parents did not want them. It is also like her finding out that her parents preferred having a baby boy to having a baby girl.

3. Unresolved conflicts often become clear during a hearing children of deaf parents adolescence and young adulthood when he or she faces issues of independence (autonomy) and identity.

All adolescents must separate from their parents and form adult identities. Separation issues are intensified in hearing children of deaf parents because of a difference in deaf and hearing worlds. They keenly sense what they are leaving and losing as well as gaining. They may mirror attitudes of parents or rebel against these attitudes. The adolescent hearing child of deaf parents may look for other controls to relieve him or her of the pressure and frightening responsibility for his or her own behavior.

As a result, the hearing children of deaf parents may turn to a teacher, neighbor, policeman, social worker, or others; may regress into juvenile delinquency or other irresponsible behavior so that others will control them and/or to get time for lost childhood; may feel differently toward the late deafened person than toward the hearing parent and act out different issues with each parent, for example, obeying one parent but not the other. He or she also may hate school and underachieve or be "too good to be true." By the way, even high-achieving hearing children of deaf parents have gone through a period of developmental regression, including juvenile delinquency. But take heart. We can get through the harrowing passage to adulthood with your help.

**Question and Answer Period**

**Question:** I have three sons. They are eleven, nine, and seven. When I became deafened they were six, four and two. The younger two don't remember when I could hear, but the older one does. I think that I have explained my deafness to them and why. But still sometimes they will come to me and they will say, "Why don't you hear," or "why don't your ears work?" They seem to have adjusted well because they all sign to me. My husband signs. We took a sign class in college when I was still hearing, so since I became deaf we have been communicating with sign. My children see their father and me signing and have picked up some signs by watching us. So far this seems very natural to them. They say, "This is my mom; I love her and she is deaf." I try to be as independent as possible by answering the phone and the door. I try to be honest with them and talk about my feelings and their feelings. Some of our most interesting conversations have been while watching cartoons together or watching a sitcom together, or maybe situations
come up and we talk about communication in a family situation. But they keep asking me from time to time why can’t I hear, even though I have explained it before. Does that mean that they really aren’t accepting or are they still just too young to understand? I watch them and they seem very accepting of my deafness. So I wonder, are they doing as well emotionally as I think they are because they keep asking why I can’t hear. Are they beginning to understand that it is not going away?

**Answer:** It seems to be related to the unbelievableness of the change in your hearing status. It has to be reinforced from time to time. At each stage of development, they seem to be asking you the same question. The reality of the hearing loss needs to be reinforced in different ways. Sometimes your children seem to accept it and sometimes they don’t and want it reinforced or explained again. It is something that is real that a child needs to believe and then reconcile. It takes time.

Several hearing children with profoundly deaf parents suspected that their parents were spies and heard everything they were talking about (Lu Ann Walker talks about it in her book). They get this feeling once in awhile. There are times when you are accepting and you are fine. And there are other times when you are questioning. It’s hard to believe your parents don’t hear you. It’s hard to accept it, sometimes, because it separates the child from the parent, which is scary, or the child feels frustrated and is not sure if it’s the deafness in the way or not. The child doesn’t want to be separated. I am different? Am I on my own? It’s scary. If the deaf parent speaks well, it may add to the confusion.

**Question:** That is one of the major problems that I have faced because I was born deaf. And my husband became deaf. We both speak well and we have a lot of friends who don’t speak well. They look at us and say, “Come on, how can you be deaf? You speak well.” Would that add to the confusion?

**Answer:** We think so. Part of it may have to do with the child wondering if they will become deaf when they grow up. It may be similar to the younger deaf child thinking that they may die or they may become hearing later on in life because all of their role models are hearing. Deaf children wonder what’s going to happen to them when they became adults because they don’t see any deaf adults; no deaf teachers in the school and so on. Well, it is reversed for a hearing child. Some hearing children want to be deaf like their parents. I remember when I wanted to go to Gallaudet. “You can’t,” my father said. Oh, that was tough to deal with.

**Comment:** I am a deafened mother of a hearing child who is now 21 years old. My advice to the parents who have children at home is to keep a sense of humor. It is so important in communication. It was a wonderful experience to raise my boy.

**Question:** I don’t have children, but I am recruited regularly by a sister who teaches different grades in school. I have noticed that the ages are different, but the kids can’t seem to understand the concept of deafness. One time, I went to the third grade class and they asked me if my ears were broken. And I said no, not really. I tried to explain why I couldn’t hear. But they kept coming up to me and asking the question a little bit differently. They would think about it then they would come back and say, “You said you had spinal meningitis. So your ears aren’t broken your spine is broken.” How to explain? My question now is: Is there a right age where kids really become able to understand the concept of “ears that don’t work right?”

**Answer:** This relates to the point made earlier about ongoing realizations and reinforcement. The key is that it’s ongoing. They may understand at one level but then they come back. You may not like the parallel, but sex education happens at different
ages, too. When they are five, they understand one thing and when they’re eight, it changes, and 16, it changes again and, really, they should keep on communicating about that. Well, they really want to understand. Maybe they have the wrong idea. They come back and ask you again. You know, they really want to know what you think. They are learning from you. Even as I learn from my deaf mother, sometimes I ask her again because I want to see my mother’s answer repeated as a sure thing. The attention was nice too. I would expand her answer and it became a part of me and I would understand something better. I think children are wanting to communicate with you and it’s difficult to know on what level to answer, just like sex education. How do you answer those questions? It is difficult. But they are watching for your attitude as much as explanation. They are watching for both. If they ask, “Are your ears broken?” You may answer: What does that mean that the ears are broken? You have a chance to feed a lot of ideas.

Also, deafness is multi-dimensional. There are so many different perspectives. It’s like the blind men and the elephant. How big is it? How does it affect your life? Where does it come from? How does your language influence culture? It’s so huge that it’s not easily answered with just one answer at one time.

**Question:** I wanted to bring up the issue of children learning sign language and some of them not learning it so well. What is it that encourages children the most to learn sign language when they have a deaf parent?

**Answer:** I think that what encourages children to learn sign language is the parents’ feeling that this is a necessary form of communication; the use of it over and over again with the children and between themselves. “This is the way we communicate.” If they misunderstand, be sure to let them know that it’s okay because you can talk to them or talk to your spouse. If everybody says, “Yes, we are committed to sign language,” I think the learning process happens faster. But you can probably think of other reasons than that. I think if it is needed, then it is learned. And if there is a cooperation in the family, then it happens faster. If it is considered secondary, “we will learn it later,” then it happens more slowly.

**Comment:** I agree with what you said exactly, but I think it is also important to provide an opportunity for the children so that they don’t become frustrated. I think in the late deafened experience, the kids don’t want to sign and it is really frustrating for the parents to continue to learn signs themselves. So I think you have to provide the opportunity to learn and educate without making communication its sole purpose. There are books on how to learn to sign English for deaf kids. Most mothers or fathers could read them to the kids. That is a fun experience. And then you can sit with them and show videotape stories with signs or take them to shows that are signed. If you know sign language is not only for communication, it may be better. It can be so frustrating, so you have to provide fun. Family vacations would provide a good opportunity to do this if you can take the time to be with your hearing and deaf children. Your children will see other children signing and that is really very reinforcing. You go to puppet shows with deaf signing. It’s fun. It becomes part of their life. “It is not something different. Other people are doing it, and it’s for me.”

**Question:** We have two children and both sign. Both are from an environment that is different. My wife was born deaf and I became deaf. So they see both perspectives well. But I am thinking of what you said before about the confusion. I sing all the time for my children. I have a good voice. I think that is confusing to them, also. Do you think that is good or bad?
Answer: Good. You give everything you have. Don’t hold back. I know some hearing children of deaf parents who talk about their parents’ singing. They love the memory of the voice and the singing. Before they were afraid to tell people that, “Really, my mother sang to me!” And they demonstrate the voice; maybe it’s flat, but they are signing and they are singing and they love it because the mother or the father is giving everything they have to them. They feel that link. You are giving them that link with singing. It’s a part of the experience that we cherish.

Question: When you were growing up, did you find that you were not accepted by the hearing children because your parents were deaf?

Answer: No, not that I wasn’t accepted. Actually I was a very good girl. I was accepted, but they would ask stupid questions that made me feel bad. Like, “Can your parents drive? How can they? Why do you spell so well? Well, I was fingerspelling when I was young. And I guess other kind of questions like that that just show a complete lack of imagination. I also had very good friends who would come to my house. They would love to come to my house when I was a teenager because we could have music in the house and no one complained. And my closest friends learned fingerspelling and signing. Even teachers too would ask questions like, “You know, you are a bright little girl. Sorry that you have deaf parents.” I felt like I didn’t want to hear that. I felt they were looking for ways to put me in a box. I didn’t like being put in a box. I felt different. Why do you ask me if my parents can drive? And then I started to feel a little bit shaky. You know how children can’t stand to be different. They all want to be the same. They don’t even want people to look at them in a restaurant. They try to be the same as other people. I think it’s more that kind of emotional sensitivity than the straight out rejection of “No, you can’t play with me because you have deaf parents.” It doesn’t really happen that way, or if so, it rarely happens.

A lot of factors influence feelings of acceptance. There’s no one answer. We were trying to define it for ourselves while we were children and, at the same time, trying to be accepted by peers.

Comment: I just wanted to add how important it is for the parents to be open minded and allow the children to talk about those kinds of experiences if they happen. I remember one time when my daughter came home from school very upset. A girl was teasing her and said that her parents would die because they couldn’t hear the fire alarm. My daughter was able to share that experience with us and talk about it. And we helped her understand it was not true. Sometimes people make those kind of comments out of ignorance, not out of intentional harm. We try to help children with that by being open to what they are talking about.

Answer: I think that is really important and more so, how you handle it. If you are open and say “People will say that and they don’t really understand,” the children feel better. If you start complaining about hearing people, I don’t know how much that will help because the children are hearing and they have to try and find their place. They have to feel comfortable in both worlds. So again, it is how you handle and talk about it.

Also giving them suggestions for handling a situation, not only telling them, “Oh that is not true.” But also give me a way to handle it too. The child says, “Help me...What should I tell them? How do I handle it?” I think that may be helpful.

Question: You are already adults in your situation. My concern is for my children who are eight and five, particularly my daughter who is eight. We get into a control issue. I know she is working through some of her feelings. And as a mother, I don’t think you
can be everything to your kids. "Why don’t you sign," I said to her last week. I said, "You think this is a joke. I have been doing this for four years and you think this is a joke." So we get into a power issue. No, she won’t sign and I don’t understand. What I am saying is I think it is important for kids in this situation to find each other. And I don’t really know exactly what to offer her. For example, right now, I am having a woman come in and teach sign language to the kids and my daughter has four of her friends join her. It’s wonderful. She is excited, but she is the one with the deaf mother. It’s a survival thing for her. It is different. How do these kids find each other. She is the only one in Boston.

**Answer:** I’m glad that we have CODA now because you go and find out “My God, you too!” You are shocked. You laugh. And finding others like you really helps. When I was little, I played with other hearing kids, but we didn’t talk about my parents in any way that really helped me. Now CODA is trying to see if we can set up a big brother big sister program. It is happening in Chicago, Colorado, and Washington, D.C. We’re trying to contact hearing children of deaf parent kids and link them up. So, it’s slowly starting up.

The CODA organization itself has just recently established a Board of Directors. One of their projects is to focus on issues for youth. There are some things that are happening. The organization itself has not made progress recommending how programs be established. But we can give you contact numbers, perhaps, in your area of adult hearing children of deaf parents and you can try to network and see what you can come up with for your daughter. That may be of some help for now, but it is not yet an official program. Some day it will be.

By the way, I think it’s great that your daughter can test you. That shows some openness. At least she is talking about it. That is important you are not injured by it. You laugh, you think it is a joke. That is a great attitude and it’s important. If your reaction is “How dare you, you bad girl. Understand? This is the way it is.” That puts a damper on any kind of communication. She is going to test you and your response helps your daughter.

**Question:** Did you volunteer to tell your friends that your parents are deaf? The reason I am asking you is that my two children just tell their friends their parents are deaf. They are proud. And it was always shocking to them in school that the kids who had deaf parents didn’t tell. I live in Jacksonville, Illinois, near the deaf school. Many of the hearing children go to the public school. And it really hurt my two daughters that the others wouldn’t tell that their parents were deaf. So I am asking you, how did you let your friends know? Did you volunteer the information?

**Answer (Dr. Shultz Myers):** I always told. I went to a small school and everyone knew it from first grade on. Kids used to ask me to fingerspell the alphabet and time me to see how fast I was. My parents’ deafness was known and accepted.

**Question:** But did you say, “You know that my parents are deaf?”

**Answer (Dr. Shultz Myers):** It was known from the first grade. The mothers all came and they saw my mother sign, plus I talked about it in school. In some classes I shared information. I remember fourth and fifth grades I used to get up and talk a little bit about sign language and things like that. I think I just said my parents are deaf. Very matter of factly, even with some anticipation of interest. A few times I got pity, which I hated. The only time I didn’t tell others, though, is when I went to graduate school. I was experimenting and I didn’t tell people for a long time. I don’t know if it was good. I wanted to compete; I didn’t want anyone to know and somehow look at me differently.
But later on, it was okay. I did tell people. And they were surprised and interested. But, I still don’t understand fully why I did that.

**Question:** What about your first boyfriend?

**Answer:** (Dr. Shultz Myers) I always told. And I did feel that when my first boyfriend broke up with me that he didn’t like the fact that I had deaf parents. Other times nothing negative happened, it was very positive. So, fine. I learned to communicate.

(Mr. Myers): Mixed. I recall keeping school and home separate. My neighborhood kids knew because they saw my parents daily. But the school situation was different, so it was separated. One time I remember my parents going to the school. They told me, “Bye, bye, we are going to go to the school now to visit with your teachers.” They came home that night and said, “We had a fine visit with your teachers.” But really what hit me strongly was when I went back to school and the teachers came up to me and said, “I met your parents, nice talking with them.” That was wonderful and a relief because that took the responsibility off of me. My worlds came together, however briefly. But the kids were different. I didn’t tell anyone other than my closest friends.

**Question:** I have three children ages 15, 14 and soon to be 12. The oldest one seems to be over protective of their father who was born deaf. I am hard-of-hearing, but I have told him many times to sign for both of us. His conversation with his father is limited to sports. The conversation to me is, “Why don’t you hear well enough if you can talk so well?” My daughter accepts her father’s deafness. She accepts mine, and she informs her friends that we are deaf. My oldest son does not. He doesn’t tell his friends. But he got into a disagreement, an argument with a boy in high school because the boy said, “Oh, your mother is deaf.” This went on and it made him angry and he hit the boy. He can’t handle his emotions enough to stay cool, let it go by, come home, and then let it out. It happened at school. He got a one-day detention because of that. My youngest son doesn’t understand the issue yet. Either that or he doesn’t care. He does not sign; he talks and expects me to know everything. The three kids don’t have a role model. They expect me to be both the mother and father. I have the last say because the father can’t express what he wants to say because he doesn’t have the education to say what he wants to say to the kids. So the kids have learned more in school than he did and when they want to share things with him, he doesn’t understand. And it leaves me in a bind. And then I have a conflict with both sets of grandparents. The paternal grandfather is trying to cover his foot steps with my last one to change how my husband was treated when he was growing up. He is trying to make up for not raising his son right. So he is trying to raise my last child, but he’s not his son. He’s mine. I am still struggling with him because we live in a two flat with the grandparents downstairs and my last one is there all the time. He practically lives downstairs. During the day he goes there and then he goes to bed at night. There is no control of what he is doing down there or what he tells his grandparents. He should talk to his father and not his grandfather.

**Answer:** This is what we were alluding to before, a three generation family. And there are so many issues that you raised. I don’t know if this is the time to go into all of it. But I guess I would support you getting somebody outside of the family to help with the boundaries. By this I mean the boundaries in the family and the authority of the father as well as your boundaries because I see in the children’s responses an ambivalence about authority, control and isolation. They are really asking for guidance and help. They are in that system too. It sounds like if you had somebody from outside the family to dialogue with you and the family, you would be more comfortable with the interactions. It sounds like people are crossing boundaries in your family. It takes time. But I would support going for outside professional support.
Question: Do you have the address of CODA to distribute?

Answer: The address for receiving the newsletter is CODA, P.O. Box, 30715. Santa Barbara, CA 93130. And the membership is $15. Associate memberships are $10 for non-Codas, but interested people like yourselves.

This is the first time we are presenting together, for your information. And we hope you have enjoyed it. We will be working on some of these issues and publishing more about this kind of information.

Comment: I am a child of deaf parents. And I just learned about CODA from Randy not too long ago. And I am happy to say that I know about it. It makes me feel like there is a support group that is much needed.

Answer: Thank you very much. Thank you for coming.
Section Five:

Accessibility
Alphabet Soup:  
Or how you can make sense of finding  
information about deafness

Lorraine DiPietro

Lorraine DiPietro, M.A.T. is currently Director of NICD. She has been involved in  
information and education throughout her career. She has been - and still is - a teacher,  
writer, editor, trainer, and project manager. Most of her work has focused on increasing  
awareness of the needs of deaf and hard of hearing people.

Information is all around us! It’s all the ideas, facts, and imaginative works of the mind  
which have been communicated, recorded, published and distributed formally or  
informally in any format. Talk about potential overload. Lucky for us, as individuals, we  
are quite selective about information pursuits. We dabble in this pool of information,  
going with the flow, rarely consciously registering it. Good thing. We’d be overcome  
with information overload. We make more conscious efforts to gather information when  
our interest is piqued, or when a situation requires.

For example:

A novice parachutist couldn’t open his chute on his first jump. As he was falling toward  
the ground, he saw another individual flying upward past him. Calling out to the  
passerby, he said, “Do you know anything about parachutes?” The man going up replied,  
“No...do you know anything about gas stoves?”

A little bit late, but nonetheless a human response. When you need to know something,  
ask a question. Obviously, we’ve found that asking questions does get us answers.  
Sometimes, we get excellent answers; sometimes we feel let down, that, somehow, the  
person we asked didn’t really answer our question(s).

Today we’ll look at information resources that relate to deafness, what they are and what  
they do, with a focus on information centers, a specialized group of information  
resources. The goal of this introduction is to help you identify the resource most likely to  
have some answers for your questions. One of my goals is to familiarize you with the  
common acronyms for these organizations—the alphabet soup of the title. A few culinary  
terms will appear as we study the ingredients in this soup.

THE BASIC STOCK OF INFORMATION ABOUT DEAFNESS

The fund of information about deafness is vast. It includes all the resources that have any  
information whether they are programs and services offered to the community at large or  
those with specific services to deaf and hard of hearing people. It helps to start close to
home when you are trying to locate information. Your community might have a number of these resources, among them:

- community information and referral agencies (I/R or I&R)
- community service centers
- hearing and speech centers
- schools or programs for deaf students

One of the most valuable resources is your local library. As part of a system of libraries with trained information professionals, libraries can help you locate information about deafness and other information resources, whether local or national, by taking advantage of their network of contacts, including professional peers and computer systems, and by locating journals related to deafness which may be in their library collection.

Going a bit higher up the scale of potential information providers to the state level, you might be able to find teacher and professional training programs with specialization in deafness. University hospitals with training programs in audiology and speech/language pathology may also serve as information providers. Quite often, such resources provide information specifically related to their professional work. Even so, they may be valuable for the referrals they can provide to local groups and professionals. In addition, schools and programs for deaf students often serve as resource centers and may have information on hearing loss in general.

Still higher up the scale are national consumer and professional organizations that publicize information as one of the many services they offer to members and to the general public. Those of you participating in this conference obviously recognize the value of ALDA. Not only is it a means of personal interaction with many different consumers experiencing late onset deafness and professionals who work with them, but it’s a source of information and support for its members and interested publics. We’ll discuss such organizations later.

If you are already a member of an ALDA chapter, then you are building a personal network of people with experiences and information needs similar to your own. Some members may have already searched for information on a particular subject and are prepared to share what they know to help you find more information. Some members may be novices. The best part of this kind of “networking”-- where you connect with people like yourself -- that you can share experiences, knowing either that someone has been there before you or that however long and hard it might be to find information, you’ll have someone to share with as you go along.

Now for a definition of terms. An information resource is any entity that collects information on one or more facets of a broad subject matter. Usually the primary audience is the organization’s members. An information center or information clearinghouse has to meet a number of criteria. These criteria are adapted from Dr. Susan Klein’s paper defining the characteristics of education-related clearinghouses, “How Can the Federal Government Help Education-Related Clearinghouses?” These criteria remind us that what a clearinghouse does is often defined by the scope of the information collection. An information center or clearinghouse is:

- a place where organized databases are maintained and continuously updated, covering a specific content, a process, or resource type(s);

- a place which maintains databases with extensive sets of screened resources in specific topic-relevant areas;
• a place where information from databases is available to the general public--nationally and internationally--possibly with minimum database search or document cost-recovery charges;

• a place where staff actively share information with constituents through newsletters, fact sheets, bibliographies, research syntheses, directories;

• a place which usually calls itself a clearinghouse, resource center, information center, or information service.

INFORMATION RESOURCES IN DEAFNESS: Some major ingredients

Following that introduction, let’s look at some of the primary information resources in the field of deafness.

Alexander Graham Bell Association for the Deaf, Inc. (A. G. BELL)
Washington, D.C. (202-3370-5220 v/tdd)

Gathers and disseminates information on hearing loss, promotes better public understanding of hearing loss in children and adults, provides scholarships, financial and parent-infant awards, and promotes early detection of hearing loss in infants. Committed to the development of oral/aural skills in deaf children.

A. G. Bell Association has a catalog of publications available for sale on issues related to oral/aural education, speechreading for adults as well as children, oral interpreting, and mainstreaming. The association also has a library.

Association of Late-Deafened Adults (ALDA)
Chicago, Illinois (312-604-4192 tdd)

Serves as a resource and information center for late deafened adults and works to increase the public awareness of the special needs of late-deafened adults. ALDA does consider itself an information center. When its database is set up, it may well meet the criteria above. The newsletter is a primary means of information sharing at this time.

Cochlear Implant Club International (C. I. C. I.)
Buffalo, New York (716-838-4662)

Provides information and support to implant users and their families, professionals, and the general public. The information provided is about cochlear implants.

National Association of the Deaf (N. A. D.)
Silver Spring, Maryland (301-587-1788 v; 301-587-1789 tdd)

Committed to improving the quality of products and services for deaf and hard of hearing people. Advocates for equal access to communication and employment opportunities; has a legal defense fund. Supports the use of sign language as a primary means of communication for deaf children and adults.

Responds to requests for information about deafness with information from its own files and will refer users to other sources. The N. A. D. publishes a newspaper, The N. A. D. Broadcaster, a magazine, The Deaf American, and occasional monographs on deafness. The N. A. D. bookstore has a catalog of materials available for sale.
Self Help for Hard of Hearing People, Inc.
(S. H. H. H.) Bethesda, Maryland (301-657-2248 v; 301-657-2249 tdd)

Promotes awareness and disseminates information about hearing loss, communication, assistive devices, and alternative communication skills through publications, exhibits, and presentations. The SHHH Journal is a major means of sharing information with its membership, offering articles on timely issues (ADA, employment, hard of hearing people in health care settings, etc.) and a forum for individuals to share their experience of hearing loss. Reprints of articles from the journal and other publications and media packages are described in a publications list available from S. H. H. H.

State-Wide Programs:

With the new legislative activity and recognition of the rights of people with disabilities, more states are establishing state-wide programs. Twenty-seven states have offices or commissions for deaf and hard of hearing people. These programs are usually a central source for information on the needs of deaf and hard of hearing people in a state and may also manage interpreter referral services, relay services, and advocate for improved state services for deaf and hard of hearing people.

In states without Commissions or Offices on Deafness, the office of the state coordinator of rehabilitation services for deaf persons is often an important resource and may be able to refer you to information sources within a state. You will be able to locate the office of such a coordinator through the state division of vocational rehabilitation.

Educational Institutions in Deafness:

Other entities which serve as valuable information resources are education institutions. Two national and several regional programs provide education specifically for students with hearing impairments and have active placement services. About 150 post-secondary programs for deaf students are now in existence. I will identify only a few major programs whose acronyms or names you may have seen already.

Gallaudet University
Washington, D.C. (202-651-5000 v/tdd)

One of two national programs for postsecondary students who are deaf, Gallaudet is a multipurpose educational institution serving deaf and hard of hearing individuals through education, research, and public service. In addition to a liberal arts undergraduate program, Gallaudet also offers masters and doctoral level degrees; pursues research on various aspects of deafness and disseminates the results of that research through reports and monographs; disseminates materials through various units—the Gallaudet Press, the Gallaudet Bookstore, the Gallaudet Research Institute, and the National Information Center on Deafness. The university library loans selected videotapes from its collection.

Gallaudet is a member of the consortium of Universities in the Washington, D.C. metropolitan area and students may cross-register at other member institutions and attend classes with interpreters.
N.T.I.D.--National Technical Institute for the Deaf at Rochester
Institute of Technology
Rochester, New York (716-475-6400 v; 716-475-2181 tdd)

The second of the two national programs, N. T. I. D. provides technological postsecondary education to deaf and hard of hearing students. Students at NTID take classes at R. I. T. with interpreter and notetaking support. N. T. I. D. also has a research arm and disseminates informational materials and instructional videotapes on deafness and related areas.

INFORMATION CENTERS/CLEARINGHOUSES: The meat of the matter

The following clearinghouses are national providers of information specific to deafness or on disabilities in general but have sub-files of data relevant to deafness.

ABLEDATA
Silver Spring, Maryland (1-800-346-2742 V/TDD)

A computerized product database identifying more than 15,000 commercially available disability-related products from 1,900 manufacturers. ABLEDATA groups its information in such categories as: personal care, educational management, vocational management, communication, transportation, recreation, computers, controls, etc. The database is searchable by disability.

ABLEDATA is developing a database on products for people with hearing loss, through a subcontract with the Technology Assessment Program at Gallaudet.

HEATH Resource Center (Higher Education and Adult Training for people with Handicaps)
Washington, D.C. (800-544-3284 v/tdd; 202-939-9320 v/tdd)

A national clearinghouse on postsecondary education for individuals with disabilities, HEATH disseminates information nationally about disability issues in postsecondary education. HEATH collects information on educational support services, policies and procedures, adaptations and opportunities on American campuses, vocational-technical schools, adult education programs, independent living centers, transition, and other postsecondary training situations. HEATH has a toll-free number and disseminates numerous publications.

JAN (Job Accommodation Network)
P. C. E. H., Washington, D.C.
Database in Morgantown, West Virginia
1-800-JAN-PCEH
1-800-JAN-INWV (in West Virginia)

JAN is a computerized information service storing accommodation experiences submitted by employers for employers, job accommodation personnel, and disabled people. JAN aims to provide accommodations information to the caller for hiring or retaining a disabled employee.

NARIC (National Rehabilitation Information Clearinghouse)
Silver Spring, Maryland (301-588-9284 v/tdd; 800-346-2742 v/tdd)
NARIC provides information and referral services on disability and rehabilitation, including quick information and referral and database searches of the rehabilitation literature and research materials in its computerized bibliographic database, REHABDATA. NARIC also provides document delivery.

**N.I.C.D. (National Information Center on Deafness)**
Washington, D.C. (202-651-5051 v; 202-651-5052 tdd)

A centralized source of information on topics dealing with deafness and hearing loss, N.I.C.D. collects, develops, and disseminates information about all aspects of hearing loss and services offered to deaf and hard of hearing people across the nation.

**N.I.D.C.D. Clearinghouse (National Institute on Deafness and Other Communicative Disorders)**
Washington, D.C. (1-800-727-NIDCD)
(Expected to start sometime in the new year!)

The new kid on the block, the Clearinghouse of N.I.D.C.D., coordinates the vast amount of information on hearing, balance, smell, taste, voice, speech, and language for health professionals, families, industry and business, and the general public. The Clearinghouse will identify information resources, develop and maintain a database, channel requests for information to appropriate organizations for response, distribute NIDCD and NIDCD Clearinghouse publications.

**A Few Spices to liven up the soup:**

**ALDs**
Assistive listening devices (ALDs) are special hardwired and wireless systems which can be used with or without hearing aids to improve a person’s ability to understand speech in noise and/or from a distance.

**CAN**
Pioneered by ALDA itself, computer-assisted notetaking is a process whereby a running copy of meeting discussion is typed into a computer and projected on a large screen for participants who are deaf or hard of hearing.

**T.D.D.**
Telecommunication devices for deaf people, TDDs enable direct communication between two people using compatible devices. As relay services are established, it becomes easier to call a hearing person who does not have such a device. A new term, TextTelephone (TexTel or T.T.) was introduced in the F. C. C. (Federal Communications Commission) regarding relay services. The term “T.D.D.” was retained in the Americans with Disabilities Act. You may occasionally see T.T.Y. (teletypewriter) the term used when the first T.T.Y.’s were made available to deaf people in the late 60’s for use in telephone communication. They all refer to the

**TESTING THE SOUP: YOU AND INFORMATION CENTERS**

Now lets make this more real and look at you and your relationship to information centers. You’ve just learned what the information centers do so that you can use them knowledgeably. Before you approach an information resource of any kind, you have to figure out:

1) Your information goal
What do you really want to know? Do you want the information for yourself or for someone else? Obviously, if you are writing a paper, the nature of the information you are seeking would be quite different from information you might want for yourself about living without hearing.

Do you want to know about general services? About programs located in your area? About organizations? Focusing your questions can really help an information specialist help you.

2) The likelihood of finding the information you want from a particular source

If you want information on post-secondary education and support services, you would contact HEATH. If you want patient information on hearing loss, the best first contact would be the Clearinghouse of N.I.D.C.D.

HOW NICD HELPS PEOPLE MAKE SENSE OF THE ALPHABET SOUP OF INFORMATION

NICD’s Experience with Questions:

In 11 1/2 years of operation, NICD staff have responded to nearly 70,000 inquiries. The questions come from the general public, people with hearing loss, their families, friends, co-workers, bosses, teachers, other professionals who come in contact with them, and the general public. These people usually have an urgent need for the information, or, a general interest. They call, write, walk-in, e-mail us on Deaftek.International, or ask questions in forums such as these.

We answer questions in different ways: with publications, either developed by NICD or other organizations; with reading lists and bibliographies; with information from reference sources; with referrals to contacts on the state level, or in a local community, if we have that level of information. About 5 percent of requests receive an individualized letter as well as appropriate materials as part of the response.

After a few months in an information center, you become familiar with the frequently-asked questions. Then, you develop an organized approach to answering them. NICD monitors the incoming questions to determine if there is an increase in certain topics and tries to locate existing material that answers the questions. If we are not satisfied with existing materials, then we develop our own publication on a new topic.

Our collection includes approximately 700 brochures, catalogs, articles, reading lists, resource lists, and fact sheets. We also have subject files on topics from “Academic Achievement” through “Wristwatches.” Our programs and services files contain information about national and state programs serving deaf and hard of hearing people. We maintain a collection of state directories which helps us refer callers to a local contact. We choose the specific item(s) which responds to the individual’s questions from this collection.

We also work with such organizations as SHHH, NAD, ALDA, and A.G. Bell to identify a specific contact for a requestor. We will refer to other information centers and organizations when we know they are the better source for information.

Some typical questions received at NICD:

1) How do deaf people communicate?
2) Where can we find financial assistance for devices, for school, for training...?

3) My father is losing his hearing. We want to maintain contact on the phone, but that is increasingly difficult. Is there any device we can use to help in this situation?

4) Where can I find out about services for deaf and hard of hearing people in my state?

5) I was recently diagnosed as having a 55 decibel hearing loss. The doctor I saw says nothing can be done. I can’t believe this is true.

6) Send me a list of colleges who cater to deaf students in architecture.

7) I’ve just learned that my child is deaf. Where can I get help?

8) My husband recently lost his remaining hearing and the doctor has advised that we get some speechreading videotapes so he can practice to develop his skills. Can you help me?

9) I’ve just learned that my child is deaf? Where can I get help?

10) Are these new-fangled digital hearing aids worth the investment?

11) How do deaf people manage in a restaurant?

**NICD’S Experience with Questioners:**

Whether the people who use our services have an urgent need or a simple interest, we respect them and their questions. Our goal is to respond within two weeks to requests. We meet that goal 85% of the time! We try to find or develop information that provides a practical response.

The majority of our users are just beginning to delve into hearing loss. Sometimes their questions are vague and we are forced to respond with general information. The more clearly defined a request is, the more specific our answers can be.

All information specialists want to have answers to questions. Unfortunately, we don’t always have answers, because our collection and resources are limited. The four full-time and one half-time staff at NICD are augmented by two graduate students and six volunteers. Sometimes there really isn’t an answer. For example, we received a call this summer about support groups for deaf people with cancer. It’s an unusual enough topic, that if such a group existed, it would likely have been publicized in national publications from deaf people and newsletters that we receive from the states. We called national cancer information sources to find out if they had any such program information. Our suggestion was to contact a licensed social worker who works with deaf people or a mental health counseling center for deaf people to identify options for the individual needing a support group.

**REFINING THE RECIPE: The Consumer’s Role in Information**

You can help information centers serve you better. I was able to develop the following suggestions only because NICD has had so much experience working with people who have real information needs. All information centers want to improve in serving their audiences. These are ways you can help.
• Tell us if our information is appropriate for you. Are we answering your questions? Are we writing to be read?

• Tell us if we have overlooked a valuable resource in one of our resource lists. We can not find every service or program by ourselves.

• Think through your questions before you call or write. Information specialists are skilled at clarifying a caller’s questions. If you write, we don’t have the opportunity to ask you questions to see if we really understand what you are hoping to find.

• Tell us a little about what you already know about a topic. That would help us choose information more appropriate for you.

• Be patient with information center staff. Information center personnel are service-oriented. They want to help and they try to provide a specific response. Sometimes, however, a center may not have information to answer a particular question. Sometimes, a “lead” might be the only response.

• Let us know if a referral did not work out for you. We try to update all our resource lists annually to be sure the programs still exist or the materials are still available.

• Sometimes the referral experience is not positive. Let us know that.

• Take an active role in evaluating services of information centers. NICD periodically samples user satisfaction. Feedback from users tells us if we are doing the job right and what changes we might have to make.

• Keep asking questions! No one remains in the same spot intellectually. Society is constantly changing and each change affects you, your family, and friends. New information must be made available to respond to questions and concerns which emerge as a result of societal change. Take advantage of that new information.

• “Thank you” helps.

• If you can’t find an answer to a question about hearing loss or deafness, call or write NICD. We’ll try to find an answer for you.

I hope that this introduction to information centers and resources will be of help to you as you embark on future information searches and look forward to receiving any questions you might have about hearing loss. Bon appetit!
References:


A note on terminology:

"Network" can mean different things. In this paper it is used two ways. In the context of "personal networks" it means interconnections among people who have knowledge and information acquired because of a specific interest and who—if you ask them—share that information with you. Library networks include (1) one-to-one or group information exchanges among library professionals, and (2) cooperative activities among libraries, such as formal and informal consortia and integrated computer systems.

"Network" can also refer to organizations and systems that link users together via telecommunications with computer controlled message switching and database access.

A computer database is a collection of information on a particular subject which is stored in and accessible through a computer. Some databases can be searched only in an organization's office. An online database is available to anyone who has been granted access to the database and who has the proper equipment, usually a computer or terminal, a telephone line, and a modem, which is a device for changing computer data into signals which can be sent over a telephone line.
ACCESS FOR DEAF AND HARD OF HEARING PEOPLE BY THE YEAR 2000: CAN WE GET THERE FROM HERE?

Kathryn Woodcock

Kathryn Woodcock, M.A.Sc., P.Eng. served as President of the Canadian Hearing Society for 1990-1991, the first deaf president of the 50-year-old agency, Canada's largest serving deaf and hard of hearing people. She was active on its Access 2000 steering committee. A former hospital administrator, Kathryn is presently completing a doctorate in industrial engineering, specializing in ergonomics and occupational safety, at the University of Toronto.

WHAT IS ACCESS 2000

As deaf and hard of hearing people, we face barriers every day. With this in mind, in the late 1980s, the Canadian Hearing Society developed the Access 2000 program. By the target year 2000, will there will be equal access and no barriers?

Access 2000 is a partnership among consumer groups (deaf, deafened, hard of hearing, and seniors) with corporate sponsors. A lot of the program’s materials are “old reliables” but the Access 2000 banner provides a new slogan and fresh focus to get increased attention. Access 2000 provides multi-media training materials for organizations wishing to train their staff to provide better access. These materials are made available for low cost or free to consumer groups around the world. Access 2000 has been officially adopted by the International Federation of the Hard of Hearing, and has spread as far as Australia.

Within Ontario, the Access 2000 coordinator also has a linkage to the Canadian Hearing Society Technical Devices department to sell some of the devices needed to provide access (e.g. TTY’s, signal devices, assistive listening systems). A Technical Devices consultant is available to make “house calls” to companies to advise them on specific systems. Finally, Access 2000 provides a forum to reward the efforts of service providers, by serving as a catchy label for tokens of recognition that consumer groups can award.

STRATEGY

There are two main strategies that have been used. First is the sector-by-sector approach. This is preferred over the approach of finding one provider in each sector (e.g. one hotel, one bank, one church, etc.). One of the major problems has been that
deaf and hard of hearing people as consumers have to be “trained” to expect access; we have suffered without it for so long. When a single provider in a sector becomes accessible, it seems that they are not rewarded by a deluge of new customers. Consumers seem rooted to their old providers by misplaced loyalty or simple inertia, and the “good apples” among providers are disappointed. As a result, Access 2000 has preferred to target entire sectors so that consumers get used to expecting that (for example) all places of worship are accessible, even though all banks may not be. This approach has extended across national borders, as CHS and SHHH have jointly and concurrently targeted hospitals in the most recent major Access 2000 campaign. Involved consumer groups all over North America can use identical kits, and when hospitals compare notes they will realize that their own local communities are part of a significant multi-national effort.

The second main strategy is that the program is “consumer-pull”, not provider-push. The Access 2000 program is actually comprised of a skeleton staff armed only with resource materials. They will not come to call on your town! To establish an Access 2000 project in your community, your local consumer associations (organizations of deaf and hard of hearing people, seniors, etc.) must decide to sponsor it, appoint facilitators among themselves, obtain materials, and begin to campaign for access in the target sector(s): in essence, to pull it into your region. The materials available to facilitators include information about deafness and hearing loss, education and training resources for service providers, technical devices (if you don’t have local vendors or mail order sources in your area), and services such as staff training (on a fee-for-service basis).

**BARRIERS AND BREAKTHROUGHS**

Deaf and hard of hearing people face barriers in their own homes; at work -- getting work as well as getting ahead; while shopping; getting health care; getting an education; in places of religious observance and places of entertainment; and in restaurants. We face barriers when we travel. Even with existing television captioning, there are barriers to exercising all of our citizenship obligations. There are barriers to neighbourhood participation, as we are hindered by more than the backyard fence. The lack of accessible alarm devices is a daily barrier to our personal safety.

This doesn’t mean our lives are “the pits”. In the last few decades, especially recently, we have seen some barriers give way to breakthroughs. However, some improvements are needed before we can truly say we have equal access. The following is intended to allow us to both celebrate and to dream, to excite us about our accomplishments and to spur us on to agitate for continued improvement, until we truly enjoy equal access.

**Telecommunications**

In telecommunications, we now have hearing-aid compatible phones and volume control phones generally available to hard of hearing people. TDD’s (TTY’s, TT’s) are available and, under the ADA, more businesses are installing them; others are becoming familiar with dual-party relay services. A relatively new invention, a computer modem capable of interfacing with basic TDD, should become more commonly available. It would be a delight to see businesses advertising their TDD number or “voice / TDD”, to expose hearing people to the commercial reality of the deaf segment, and to encourage deaf patronage. Currently, even government departments don’t universally advertise their TDD numbers.

The “TDD” should be renamed. This unlipreadable term is mangled more regularly than any other deaf-related term. The old term “TTY” stood for tele-type, and a typing
telephone is pretty much what it is. The Deaf culture would be thrilled to see the usage return to TTY since that term has cultural value to them. "TTD" (telecommunications terminal for the deaf) and "TT" or "TTP" "text telephone" have been proposed by various phone companies and indeed by ADA, but these are still acronyms that have to be explained. I often simply call mine a "keyboard attachment for my phone". Hearing people need a word instead of an acronym.

The exciting opportunity of a level corporate playing field posed by e-mail (electronic mail) appears to have given way somewhat to voice mail. However, most businesses now have a fax, and most deaf people should investigate the increasingly affordable option of a simple fax for the home.

Emergency telephones and intercoms are still barriers. Why can we not pick up a public phone and use its keypad to type some commonly understood "SOS" tone? The "9-1-1" system can pinpoint our location, but how do we first convince the operator that it is a deaf caller in trouble and not a vandal playing with the public phone set?

Public Building Facilities

Fire and evacuation alarms are still only acoustical in most public buildings. For example, the Fire Code in Ontario requires voice communications throughout high-rises (to inform occupants whether to stay or evacuate -- to avoid casualties due to smoke inhalation in evacuation routes). Apparently we need to wait for deaf casualties before we realize that there needs to be a visual alternative to "voice" communication. If we succeed in access by the year 2000, all public buildings will have visible fire alarms and evacuation message display in central areas on each floor, and in every hotel room. There is no technical barrier, but evidently there is a deficiency of will to act.

Public TTY/TDD telecommunication need to be more available, and shelf and power outlet provided near public telephones (for bring-your-own-TDD), or public TDD provided. However, while some phone companies are increasing the number of public TDD's, others are removing them. To handle health and security emergencies, as well as provide the same degree of amenities as provided to hearing guests, hotel desks must be able to receive incoming TDD calls from guests.

Assistive listening systems are needed in more facilities. Acoustics are needed for more than enhancing the pleasure given to all by the performing arts; hard of hearing people require minimal environmental noise for optimal use of hearing aids. All lipreaders require good lighting. As with fire alarms, the lighting and acoustic needs of deaf and hard of hearing people should be considered in the building codes, since architects rarely depart from these unless specifically demanded by a client.

To avoid obliging deaf and hard of hearing people to ask for directions that might be impossible to hear or lipread, public facilities and transport systems must be well-signed. Transit vehicles should visually indicate next stop and destination, and airplane boarding calls should be made visually as well as audibly.

Communication

First, a person providing some service needs to be aware of the existence of deaf and hard of hearing people. Then he or she needs to be able to identify a deaf or hard of hearing person as such, upon encountering one. Finally, the person needs to have the communication skills necessary for effective communication with a deaf and hard of hearing person. This means how to speak with "readable" lips, when to get a pencil and paper, and a little bit of fingerspelling wouldn't hurt. Primary schools should teach
fingerspelling to hearing children. At more advanced grades, hearing schools should
cover deaf culture in social studies and health studies should extend beyond ear
physiology to also cover the means of communication with a hard of hearing or deaf
person.

"Conversation mandatory" systems should be re-thought, with consideration to ways of
providing services in "conversation optional" ways. The automated teller machines are a
good example. Another example is to allow a person to fill in their own computerized
registration screen rather than answering questions posed by a clerk at the keyboard.
Pointing menus or computerized transactions should be made widely available in
commercial situations. Priority should be given to reducing the verbal communication
needed to use public transport.

Soon, captions will be decoded in every television. This will be the second wave of
revolution in entertainment and information for the deaf public, since the introduction of
closed captioning. First-run movies should also be subtitled or "captioned" on a
secondary screen. The current lax standards of how much television news and features
must be closed-captioned should be reviewed. Is it not as important to hear politicians'
direct quotes as analysts' bromides? Late-breaking stories not pre-captioned are as
important to the deaf as to the hearing. Live theatre should offer assistive listening
systems, and provide surtitles (captions above the stage) or interpretation of selected
performances. More musicians should follow the lead of some artists, and caption their
videos.

We need better ways of being notified about important events, such as disasters and
escaped murderers. The media and police and fire departments need better means to
communicate emergency information to identified "deaf" households, but also to the
community at large, so that we may visit friends and family with confidence. What
about "captioned radio": an alphanumeric display that we could install in our vehicles to
receive emergency messages, traffic bulletins, and the like?

Interpreters must be available in adequate numbers, and adequately funded. This is
especially critical for education. A reasonable source of funding must be established for
interpreters serving deaf people who are self-employed or employed by small
businesses, to avoid placing them and their employers at competitive disadvantage. We
need more print interpreting resources (that is, qualified real time captioning) and we
need to call them interpreters to recognize their role in our communication situations and
lead towards professionalizing their service. Such interpreters need to be certified using
standards similar to sign language interpreters. The same applies to dual-party relay
operators. This group of people are rarely recognized as interpreters, yet they actually
interpret from type to voice, in the same way that a sign interpreter interprets from sign
to voice. Is union seniority enough to qualify for this position? The day has passed
when charitable generosity was an acceptable substitute for professional skill.

Employment Equity

Deaf and hard of hearing youngsters need good career preparation and deaf and hard of
hearing role models. Most existing role models, especially for residential students, are
professionals associated with schools and rehabilitation, but deaf and hard of hearing
youngsters need to see that they could aspire to careers in accounting, engineering, and
law as well. The trend towards information technology appears to have the potential to
open careers to deaf and hard of hearing people.
Jobs should as far as possible be designed to be accessible. Where this cannot be done, individual jobs must be modified as far as reasonable to accommodate a deaf or hard of hearing person who has all of the other qualifications.

**Adaptation Technology**

Technology development should shift its focus from rehabilitation to technology for adaptation and accommodation. We need to reduce the mindset that deafness and hearing loss are pitiable handicaps requiring medical "repairs". They could be minor considerations if better access to our environment could be attained through the use of adaptive technology.

Among the adaptive technology that we currently have, we must produce better, more easily available, more flexible, and cheaper signalling systems, and we need specialized signalling systems to support a variety of occupations. In many cases, present occupational barriers could be broken down by interfacing alternative outputs to existing systems. An example would be to connect nurse-call system and IV alarms to vibrating and digital pager technology. Presently, it is easier to screen deaf and hard of hearing people out of bedside nursing! Can we afford this with an aging population?

**FORECAST FOR THE YEAR 2000**

There is too much to be done, unless something changes. We must be ready to assert our legal rights where necessary to create initial access. (Some consumers need to be strident to pave the way for moderates.) We also must use market forces to reward accessible services and encourage others likewise to make accommodations.

The greatest impact can be made if consumers act in unison to bring the remaining barriers to service providers' attention. Consumer groups in every community are encouraged to use Access 2000 materials to economize on Access campaign preparation and increase consistency. Unless we work together, the target year 2000 may only be a slogan, but by cooperating and making good use of a common approach, we have the chance to make Access 2000 a reality.

The author requests that readers address inquiries to:
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Section Six:

Communication
USING VCO WITH RELAY SERVICE:
AN INTERACTIVE WORKSHOP

Greg Kimberlin
Judith Tingley

Greg Kimberlin was deafened at age 18 while in the U.S. army. He has attended Gallaudet University, California State University Northridge, and the University of Southern California. He is a licensed psychotherapist in private practice, having previously founded and directed both the Mental Health Program for Deaf, Deafened, and Hard of Hearing Persons in Southern California, and a special halfway house for deaf youth, Self-Actualization Institute for the Deaf. He is a heck of a good skier, and enjoys travelling as well as meeting new friends everywhere.

Judy Tingley became deaf when she was 17 when struck with pneumococcus meningitis. She attended Gallaudet and San Francisco State and taught in Santa Fe, Rochester at NTID, and in Sacramento. She also managed California's rehabilitation programs for deaf persons (thanks to a gentle push from Greg!) for several years before moving over to the private sector where she is now President for Teletec International in Great Britain. She loves to travel and get involved with different cultures and sign languages, enjoys playing the piano and international circle and line folk-dancing.

This workshop encouraged participants to share experience in taking charge of the telephone conversations they conduct with assistance from relay operators, with special attention to the use of voice carryover (VCO). At the end of the session an actual relay call was placed to and from two telephones in the room. The following is a summary of the far longer workshop dialogue.

GK: Greg Kimberlin
JT: Judy Tingley
WP: Workshop Participant(s)

GK: Good morning! I became deaf at the age of 18 years and at that time there was neither a relay service or even a TDD. Calls had to be made by me calling and talking into the phone, hoping the person I wanted was on the other end of the line. I would ask them to call me back and when I felt the phone ring I would answer. This can backfire. For example, I called my girl friend, said many nice things to her, and later found she hadn’t received my call. Someone in Southern California got a lot of “sweet nothings” in their ear! Those of us who are deaf can be much more excited about new technology that allows for more meaningful telephone communication.
JT: I became deaf when I was 17 and didn’t like depending on others to make calls for me. I had no control over my communication, and since I was a teenager, it really bothered me. Now, telephone communication is still emerging for deaf people and still needs improvement. Perhaps ideas will come from this workshop that will further improve relay services. As a point of clarification we will be using some terminology: “TDD” for Telecommunication Device for the Deaf, “GA” to indicate turntaking in a TDD conversation, and “SK” to reflect that we are ready to sign off. Relay is like a telephone interpreter that allows us to communicate on the telephone with someone who doesn’t have a TDD.

GK: Now there is a new feature in relay services called Voice Carryover, or “VCO” for short. I can use my own voice and the other person can hear me. To respond, they talk and the relay operator types what they say to me. It is a wonderful technique because it’s faster, easier, more personal, and you have more control over the conversation. You can project yourself so much better.

JT: How many of you have used relay service? VCO? Do you have spouses, children, or co-workers who help make calls for you? Would someone be willing to share with us their experience using relay without VCO?

WP: My first relay call was to my father-in-law. He said, “I don’t give money to that organization!”

WP: I called for my sister who went to a gynecologist. I didn’t know what the doctor’s gender was and she became embarrassed because the operator was a man and not a woman.

WP: I am a nurse and I needed to talk to a patient and needed to know if the relay operator was a man or a woman because it was a sensitive issue.

WP: I’ve never used relay service but am interested. What do you think about the deaf person who calls for information through a relay service but the other person keeps hanging up due to the delay?

WP: When I first began using it, the other person would say “Tell Holly....” I would ask them to talk to me direct. I know it is hard to talk through a third party. It is better if I can make my own calls and appointments. I never know if the operator is a man or a woman.

GK: Let’s address our expectations...and the hearing person’s expectations. Good point...most hearing people are fearful. I say, “Hi, this is Greg.” (I’m calling to a married couple) Is this Bob or Donna? It is me, Greg...you remember me.” They forget I can’t hear them. We have to clarify that they should talk to us direct and not to the relay operator. What are your preconceived ideas and expectations? The relay operator must be skilled and not conduct side conversations with the other party...should not ask questions after the call. Should not disconnect us if they don’t like us!

JT: I want to feel directly connected to the other person. I want to forget there’s a third party and I want the other person to forget it, too. If the operator is a male, that serves as a reminder to the other party that there are three of us in on the call.

WP: I would like to get the idea of the other person...we can get the words but sometimes it becomes very important to know how the other person is feeling.
Sometimes we will ask the relay operator at the end of a call what the other person sounded like...tone of voice, and so on. Sometimes the operator will say they are not involved and can’t answer. But if a TDD-user is saying I want to see all of that, then the operator should share it. I may not want to continue the conversation if I am made aware of how the other person is coming across.

**GK: Good point...I expect that the operator will use the same words and language and pronunciation.**

**WP: I always thank the operator when the call is finished.**

**JT: You are bringing up good points. There is a difference in operators, with some fearful of adding information while others do it. This is a judgment call.**

**WP: One time my aunt called me and I had no idea she was crying because of my uncle’s illness. When the operator told me she was sobbing, it was very helpful to me.**

**WP: I think it is not clear when it is helpful or not for the operator to give out that kind of information.**

**JT: We have the same dilemma when using interpreters.**

**GK: You are right, interpreters gripe because we change our minds in different situations, or from one deaf person to another. We need to spell it out in the beginning.**

**JT: When we make a call, it is not possible to convey feelings as we are typing and there are all sorts of feelings in the deaf person, in the hearing person, and even with the operator.**

**GK: Yes, there are times when we have just finished a fight with our spouse and we are stressed, and we may displace this onto the relay operator, consciously or unconsciously. While we are not “bad” people just because we are deafened, we may be angry for just having to depend on a TDD, or the relay operator, and this can create internal confusion that is both bewildering to us and others. Then we may realize we are displacing anger inappropriately, and when we try to clear the air, we have only marginal success.**

**WP: Right, for example when I say at the start my name is Elizabeth, and two seconds later I am asked, “Who is calling?” Then I start to wonder why wasn’t my name given to the person I called? I want to know the best way to make things smooth without making the relay operator mad!**

**GK: I’ve had success in solving that by putting information into the memory component of my TDD. When I dial the relay, I just hit the memory number, and out comes all of my instructions for how I want my call handled. “I wish to use VCO please for all calls. If it is an answering machine, there is no need to type their message to me, just alert me to when I can begin leaving my own message. If it rings more than 6 times, please abort the call and we can proceed with the next one.”**

**JT: Wow, you almost have to write a book just to make a call!**

**WP: Sometimes in the middle of a conversation, for example, you are making an appointment and you’ve given your name and they ask again. Has anyone experienced that?
WP: I say to the other person, “I just gave you my name and I don’t know if the operator said it.”

WP: Then it gets bad...the operator comes on in parentheses and says “I told her the name.”

JT: That can be very aggravating! You lose sight of the original purpose of your phone call. Sometimes you have to try to muddle through. You can always ask to speak to the supervisor and have them step in and take care of it.

GK: Turning now to the use of VCO, I often experience a delay and think the operator has forgotten to set up VCO and we are still in straight TDD mode. I am talking but not getting any response. This can be very upsetting. What I usually do, is ask right at the beginning of the conversation, “Hi, Bill, can you hear me? GA” When there is no response, I must frantically talk, and then re-engage the receiver in the cups and type, “Operator, are we in VCO mode?” Frequently I get a response from the operator such as, “Sorry, I forgot to switch you to talk mode.” At other times, I get angry because the relay operator will either not respond, or will even disconnect me altogether.

WP: I had things like that happen when I first used VCO. I felt like a guinea pig! The relay operators seemed to be muddled, and I am having enough trouble trying to complete my call and do not have the time or money to educate the operators!

JT: Have you talked to a supervisor about that? There are a lot of hearing impaired persons out there: deaf, late deafened, hard of hearing, and some just get on the TDD and type only. This means that the majority of calls go through the relay just using the TDD, and not the VCO. Even if it’s not perfect, it may help the operator’s skills if we use the VCO more often.

WP: I don’t think relayed calls are personal. I must leave credit card numbers for a hotel. Can I trust this person, is it an ex-convict? We have to trust the person at the relay with a lot of confidential information.

GK: We need to speak up not only for communication purposes but for cultural reasons. There is a great diversity in the relay-using population. What training do the operators have about working with customers? What stereotypes are they dealing with...all deaf people ‘look’ alike? A few months ago I went to Hong Kong. I talked with a travel agent. I also wanted to make reservations for ski trips. After getting the information and completing the call, the operator asked me, “How can you afford to go to Hong Kong and to ski?” I told her I sell drugs! You need to be blunt. They are human but should not become involved in private communications.

JT: There is diversity in the population, and also in the relay services and operators. Who lives in a state with 24 hour service? Some are from states that rely on a local service in a community center or may be run by a church or a charity. It is hard to be critical with volunteers.

WP: What about privacy...can you talk to a doctor about abortion? At a church-run service, the operator may not be willing to handle such a call. The TDD-user should feel comfortable about talking through the service.

GK: How many of you have tried putting your instructions into the memory of your TDD? Do you ask to know the tone of the voice? You can ask for this.
WP: After completing a call I once asked an operator about background sounds and was
told there was a baby crying. If I had known that sooner, I would have offered to call
back.

WP: What about swearing? One operator I had said she was a volunteer, and my call
was placed on a Sunday and I used a word she did not approve of! I told the operator I
was swearing and she said she was an operator and it being Sunday she disapproved!

JT: You are talking about a volunteer service. Would that happen if you had VCO? To
move on, who explains to the other party that you are using a relay service? Do you do it
yourself or let the operator do it?

WP: In Virginia, that is part of their training. That bothers me because I am becoming
more skilled. They ask people that I have called often if they have used the relay before.
That's a waste of time.

JT: Sometimes I want to do the explaining...I may not want the other person to know I
am deaf. For example, if I am responding to a classified ad, or arranging for some
gardening work...after all, I am a deaf woman who lives alone so personal security is an
issue. And, let's face it, we may also be concerned about discrimination. Other times, I
don't worry about such things. But it's up to me to decide.

GK: There is another factor with VCO and that is turmtaking. I call Bob and say, "Hi
Bob, this is Greg." He says "Hi, Greg." But he doesn't say GA. So I tell him he needs
to say GA when he is finished. He says, "Oh, good to talk with you" and again doesn't
say GA. I tell him that I need to type again "and you must use the GA if we are to
converse." Gee, sometimes hearing people can be very slow!

WP: But to be fair, I feel lucky because my state has good relay operators. One told me
of a baby crying in the background or that the other woman had laughed. I was really
surprised to get these non-verbal cues. Can you tell the operator you want them?

GK: I have never asked for it. Unfortunately, if it isn't done right, you can't tell
whether it is coming from the operator or the other party. Ninety-five percent of the
operators do give non-verbal cues.

JT: They should use parentheses when interjecting such comments so you know where
they are coming from. Do you think it is reasonable to ask the gender of the relay
operator, or to request a skilled operator right up front? I think it is reasonable to ask for
good service. I want a woman's voice because if it is a man, it reminds the other person
that a third party is involved.

WP: I ask if it is a man, and if so, I hang up and call back until I get a woman.

JT: How many of you use the relay service for job-related calls? Do you use VCO then,
too? If so, why do you prefer it?

GK: The people I call say they prefer it...they like to hear me using my own voice.

JT: Should we check with the hearing person later to verify information we have covered
in the relayed call? I feel it is important to know what the relay operator actually said if
we are not using VCO.
(At this point, an actual VCO/relay call was demonstrated, using two telephones in the room.)

WP: You were using your voice, Greg, and the operator was typing what the other person said. My question: is all of that on your printer tape?

GK: Only what she said is on the tape.

WP: Oh, yes, that’s a problem.

GK: Why?

WP: Sometimes the other person is giving information that is very important and you have to write it down.

GK: Well, welcome to the real world! Hearing people must write down every day.

WP: I guess I’ve just gotten used to having it all in print!

JT: Another question...can the operator hear you when you use VCO?

WP: Yes.

JT: That will change in California because the new specifications say that the operator should not be able to hear the voice going through. This makes your call 50 percent more private.

WP: You’re saying that you can have VCO with privacy?

JT: Yes, in California there are totally new specifications that were prepared by consumers.

WP: In Alaska we are in the process of establishing statewide relay services. I called the company that will set it up and asked if they will have VCO. They are not committed to it and it will depend on the money. Can you give me specific things to ask for?

JT: Ask for a copy of the California “Request for Proposals.”

WP: I want to tell you about a Direct Carry Over in my state. You can use it with touch tone phones like when you want to call your bank. The operator can’t hear your voice and you can use the number pad to enter your account.

GK: That’s wonderful. You’re totally in control.

WP: Yes, you can call the Washington Post which has so many services such as weather reports, stock reports.

JT: The Illinois Relay was featured in an article about a deaf man with a pacemaker. He needs to have it checked periodically by telephone. He does it through the relay.

WP: What about a national relay?
JT: That is part of the Americans with Disabilities Act and the FCC is working on requirements now. Send a letter to Paul Taylor and ask that VCO - with operator privacy - be one of them.

WP: In my state I want to pick up the receiver and voice my request to the operator and conduct my relayed call without ever typing on a keyboard, but they tell me I TDD then go to VCO afterward.

GK: In my state we have to do the same thing, and return to type mode every time we end a VCO call. I was happily surprised when I made a call here and found I could go straight to voice.

JT: Find out how your state does things. We see more and more opportunities to control our own conversations. If we are not given control, we must ask for it. Tell the relay operator what you want done. I have here the instructions from one state’s relay service for using VCO. They tell you that both parties should say GA each time to indicate turntaking. I don’t think that is natural. If any of you want telephone numbers for relay services all around the U.S. write to David Baquis, Teleconsumer Hot Line, 1910 K Street NW, Suite

WP: Has anyone developed instructions for hearing people? The telephone company should have something we deaf people can copy for other hearing people...to show them how to use the relay system. Everyone of us should go home to our local newspapers and ask that an article be written about the relay and VCO.

GK: That’s a great idea, and it should be repeated about every six months as hearing persons easily forget when they are not called often.

WP: I wrote one for my doctor so he would know what to expect.

JT: Actually, in California the instructions are given right in the front of every telephone book. It is great for those who are not familiar with the service.

WP: I was hoping we would have some “Amy Vanderbilts” in the room. I have a specific question: I hung up on the operator after four rings and then I thought maybe I was rude.

GK: No, I don’t think you were rude. Hearing people have the right to hang up at any time on the ringing phase, so the relay operator would be aware we can abort the call at our whim. You may recall earlier I had instructed to end the attempted call at the sixth ring. Either way is fine.

WP: That was my reason for hanging up. Good, now I feel better!

JT: This whole thing is new and involves all of us. Go for it. Thank you for coming and sharing.
SPEECHREADING: SURVIVAL TOOL FOR LATE-DEAFENED PEOPLE IN THE MAINSTREAM

Barbara Liss Chertok

Barbara Liss Chertok has been speechreading her way in the mainstream for over three decades since she was deafened suddenly at the age of 21. Five years ago, she began teaching speechreading at Montgomery College, Maryland, and privately at her home. She is a staff writer for The Voice magazine, and a consultant, lecturer, and author. She is also a Certified Reverse Oral Interpreter, and was the first hearing-impaired juror in Maryland.

History
Speechreading is far from a modern invention. It was practiced as early as 1500. Speechreading has been taught formally for centuries and probably has been learned informally since people have used speech as a method of communicating. Back in the 1930's, speechreading was quite popular. But hearing aids came along, and speechreading took a step backward. People began to think of the hearing aid as a panacea for the hearing-impaired person. Recent research has indicated that the combination of aided hearing plus speechreading can enhance communication greatly. People without usable hearing, however, can also benefit by improving their speechreading skills through formal instruction.

Definition
Speechreading is the art of perceiving speech by watching the movement of the speaker's mouth, by observing all visible clues, facial expression, gestures body language, and situations... and by listening, when possible.

Analytic Versus Synthetic Approach
Unlucky is the hearing-impaired person with an analytic mind who tries to master speechreading. The analytic speechreader demands verbal accuracy before attaching meaning to an impression. Trying to speechread word-for-word what is being said, does not work. The limitations of speechreading are many and demand a synthetic approach. Lucky is the hearing-impaired person with a synthetic mind who is able to observe and utilize all verbal and nonverbal clues to gain understanding of what is being said.

The mind plays a more important role in speechreading than the eye. In real-life situations, the hearing-impaired person must speechread for thought or context, filling in with the mind, what the eye cannot see on the lips. In speechreading, we do not merely
recognize a series of sound movements when someone speaks. We must find meaning and derive understanding from various pieces of information: the situation, the topic, the facial and gestural clues of the speaker, the visual speech movements, and when available, the supplemental auditory signal.

The Phonetic Alphabet
There are 26 characters in the English alphabet, which make up the 43 basic sounds in the English language. Only 28 different speech sounds need to be memorized because several sounds are formed with the same shape of the lips. By mastering the phonetic alphabet, the speechreader gains a solid foundation of how speech sounds look on the lips, how they feel when they are produced, and how they sound when there is residual hearing.

Homophenous Words (or Homophones)
Alexander Graham Bell coined a word to describe words which look alike on the lips. “homophone”--not to be confused with “homophone”, which means to sound alike. Because 50 percent of our language is made up of homophones, or words that look alike on the lips, it is important to encourage hearing people to speak in sentences, rather than in single words.
Some examples of homophones are: pat, bat, mat
face, vase
shoes, juice, choose

Nonverbal Clues
The old term, “lipreading”, was changed to “speechreading” because the speechreader must read more than just the speech movements of the lips. As people speak, they use nonverbal clues to convey their message. For example:
• Facial Expression: We all know what raised eyebrows mean.
• Gestures: We all know what “thumbs up” means.
• Body Language: We all know what the shrug of a shoulder means.

What about environmental clues? Conversation at the bank will be a lot different than conversation at the dentist’s office. Here is where your anticipatory skills come into play. Thinking ahead is another important part of speechreading. The clues are there. It is up to the speechreader to make use of them in order to facilitate communication.

Mirror Practice
Your mirror can be your best friend. Of course, you can read your own lips in the mirror. After all, you know what you are saying. The purpose of mirror practice is to help you identify the movements of the different speech sounds on your own lips first. Then, you will then be able to identify them on the lips of others. By “others”, we refer to the clear speakers, not the mumblers. Unfortunately, the mumblers outnumber the clear speakers by about a hundred to one! When you are able to mentally visualize the 43 different basic sounds in the English-language on your own lips without having to look in the mirror, you will then have mastered the phonetic alphabet and have acquired a solid foundation of speechreading.

In class, a good-sized hand mirror with a handle is held at half an arm’s length and at eye level, allowing the student to observe all movements of the lips, jaw, tongue, and teeth. At home, a large wall mirror is recommended. A three-way mirror is especially helpful for profile practice.
COPING STRATEGIES
1. Communication Strategies

Communication is a two-way street. The main focus of communication strategies for hearing-impaired people should be on the interactive and personal aspects of hearing loss. The bottom line is: How hearing loss affects hearing-impaired people and those with whom they interact, how well they handle communication problems, and how to keep the communication flowing.

Remember, it's the combination of speechreading skills and strategies that make you a better speechreader.

Some examples of communication strategies are:

1. You do not understand the first time—"Please repeat that."
2. You do not understand the second time—"Please rephrase that."
3. You get some of what is being said—"What did you say after the word 'blue'?"
4. You miss only a small part of the sentence—"What time did you say we will meet for lunch?"
5. You have no idea what the person is talking about—"What is the subject of the conversation?"
6. You get everything but the subject—"Are you talking about the movie we saw?"
7. The sentence given is too short for you to follow—"Would you elaborate on that?"
8. You think you got the details for an appointment, but need confirmation—"I'll meet you at your office on Wednesday at one o'clock."
9. You do not understand the number given—"Was that one, five or five, zero?"
10. You did not get the person's name—"Would you kindly spell your name for me?"

2. Environmental Strategies

When you enter a room, do you immediately size up the situation by asking yourself: Where shall I stand or sit? Where will the action be taking place? What about the lighting, distance, background noise, distractions, etc.?

Some examples of Environmental Strategies are:

1. Sit or stand near the speaker(s).
2. Sit or stand away from auditory or visual distractions.
3. Light should be on speaker’s face, not yours.
4. Have your back to any windows in the area.
5. Request lights be turned up, if room is too dark.
6. Inquire whether sound systems, captioning, interpreters, etc., are available; if so, make use of them.
7. Make a mental note that the next time you purchase a hearing aid(s) that it comes equipped with a T-switch in order to be able to utilize sound systems which are becoming more available.
Assertiveness
In order to use coping strategies successfully, the hearing-impaired person must be assertive. The steps to becoming assertive are: admit to a hearing problem; explain the problem to others when communication problems arise; and suggest ways to facilitate communication.

Some examples of Assertiveness are:

1. Person is mumbling—"Would you speak a little more clearly and slowly for me. please?"
2. Person is chewing gum—"I will understand you better, if you remove the gum from your mouth."
3. Person is chewing food—"will wait until you finish eating, so that I will understand you better."
4. Person does not face you while speaking—"Eye contact helps me to understand you better, so please face me when speaking."
5. Person covers mouth while speaking—"If you move your hands away from your face, I will be able to read your lips more easily."
6. Person is much taller or much shorter than you—"Let's sit down so that I may read your lips more easily."
7. Person has a foreign accent—"May I ask where you are from, so that I may understand your accent better?"
8. Person has a very long moustache—Bring your scissors!

The Limitations of Speechreading
Consider this: Fifty percent of the English language is made up of homophones, or sounds or words that look alike on the lips; 25 percent of our language is made up of speech sounds that are not visible on the lips, because they are placed back in the mouth or in the throat; which leaves 25 percent which is lipreadable. The limitations of speechreading are many.

Some examples are:

1. The swift pace of speech.
2. Everyone has his own way of speaking.
3. The profusion in the English language of homophenous sounds and words (homophones) -- sounds or words that look alike on the lips.
4. Low visibility sounds and words -- sounds or words placed behind the teeth or back in the throat.
5. Difficult-to-speechread proper names, numbers, idioms, slang, and foreign words.
6. Speaker limitations: mumblers, "ventriloquist" lips, deadpan expression, mouth-obsuring facial hair, facial and dental abnormalities, no eye contact head bobbing, downward chin tipping, etc.
7. Environmental limitations: lighting, seating, distance, distractions, etc.

The Oral Interpreter
In 1982 the author had the privilege of being chosen as the first hearing-impaired juror in Maryland. The trial lasted for four days, during which time she relied completely on her speechreading skills by using an oral interpreter, paid for by the court.
An oral interpreter is a support specialist who is trained to silently repeat the words of a speaker—using appropriate facial expression, natural hand gestures, and body language—for the benefit of a speechreader. The oral interpreter was allowed to sit facing the author in the jury box, silently repeating everything being said during the trial, while the author read his lips. It was exhilarating as well as an educational experience. It was also exciting because this unique situation created a lot of media attention. Shortly after the trial, one of the lawyers was quoted in the newspaper saying he felt that the hearing-impaired juror probably understood more about what was going on in the courtroom than anyone else there, except for the judge. This story illustrates what an important communication tool speechreading can be for hearing-impaired people.

The Reverse Oral Interpreter
In 1979 the author attended the first Oral Interpreter Workshop Minneapolis, Minnesota, where the first fifty-one oral interpreters were certified. Eleven were also certified as reverse oral interpreters [Certified Oral Interpreter: Visible-To-Spoken (COI:V/S)].

A reverse oral interpreter is a professional support specialist who is called upon to speechread a person with impaired speech, and then voices the message for the benefit of hearing persons. An example of where a reverse oral interpreter could be used would be in a hospital to read the lips of a patient has had had a laryngectomy or a tracheostomy.

How To Become A Super Speechreader

Ten important things to remember:

1. In speechreading, the mind plays a more important role than the eye. Train your mind to fill in what the eye cannot see on the lips.

2. Speechread for thought -- not word for word.

3. Ask people to speak in sentences, not isolated words.

4. Give feedback to the speaker. Don’t just say “what”?

5. Use your peripheral vision to observe all verbal and nonverbal clues, while focusing on the mouth.

6. Use your residual hearing as much as possible. The combination of aided hearing plus speechreading skills greatly enhances communication.

7. Be assertive without being aggressive.

8. Think ahead and try to anticipate what the speaker might say.

9. Don’t be afraid to take a guess. You just might be right!

10. Have a sense of humor. Learn to laugh at your own mistakes -- we make plenty of them.

The art of speechreading can be learned, but it requires three things from you to be successful:
1. Motivation
2. Perseverance
3. PRACTICE

In closing, let’s remember: “It’s not what you have, but what you do with what you have, that counts!”