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## A THEORY OF EVERYTHING ABOUT DEAFNESS

Tom Goulder, Mary Clark, Jeanne Naglewski

Tom Goulder: The Research And Training Center For Hard Of Hearing Or Late Deafened Persons was established eight years ago in 1994, and was based at the California School Of Professional Psychology, which is now known as Alliance International University. Our center is now located at National University in San Diego, where I am currently employed.

I have been involved with hearing loss for a long time and we feel we have reached a crossroads. In the 1960's and 70's we had the founding of National Association of the Deaf by Fred Shriver. Then in the 80's came Rocky Stove, who founded SHHH, Self Help for Hard Of Hearing People. That was followed, also in the '80s, by Bill Graham who founded ALDA, the Association for Late Deafened Adults.

I have been around as each one of these organizations has emerged. In the 1970's, I was interpreting for the National Census of the Deaf, and I wrote Fred a letter asking, "When will we would be finished counting noses?" We were identifying how many people were deafened in the United States, as well as sub-categories of deafness. One definition, which was not in that census, was the definition for late deafened. I have two definitions, one early deafened, and the other late deafened.

Early deafened to me is someone who, as a child, acquired language and then through disease, accident or trauma, lost their hearing before adulthood. When we talk about late deafened, we refer to those who became deafened after adulthood.

The reason I'm belaboring this point is because some researchers complain about our numbers. The Federal Government is really the one that came up with the numbers of people who are hard of hearing, late deafened, or culturally Deaf. There are approximately 22 million people who have a hearing loss in the United States, a number, which increases, of course, as the populations grows. The culturally Deaf population, who are born Deaf, use American Sign Language and are the smallest group of those with hearing loss.

Approximately four to five hundred thousand persons fit into this category. The late deafened are a much larger group. The government often estimates that 50 percent of

hearing loss as we know it, is due to genetic causes, and in our study of hard of hearing people, those who went from hard of hearing to late deafened are the largest group.

The late deafened group is so diverse because we have people ranging in all different age groups who have become deafened. Many things factor into hearing loss. Such as, age of onset, cause, family structure, social economic levels, and the predisposition or the personality of the person before they became deafened.

Our center did a research project centering on focus groups. In those groups, we discovered a lot of information that came directly from people who had become deafened. One of the main questions we asked was for people to pick the one thing that would be helpful in terms of coping with their deafness. And the most common answer was that people wanted to find and join a support group, or find someone else who had had this experience. For it is through that experience that personal identity is forged. There is a gray line between the time that one loses their hearing and how we evolve and gain a new identity. Many people said that what they needed was one stop shopping—a place to go where they could get all of the information and all of the help that they needed in one place. I don't know if that's fully possible.

One of the ways we responded to that need was to suggest we do a service directory, which we produced for two states: California and Florida. These service directories were very useful at one point in time, but the information changes rapidly and becomes outdated. So, how do we solve this problem in late deafness, in building a system that really works? One of the dreams that we had was to set up interventions that would help people adjust to their hearing loss. One was to set up weekend retreats, where people who were newly deafened and their families would come together and talk together and meet professionals in the field. At this time I am going to ask Mary to talk a little bit about how we went about setting up these workshops and what they meant to the participants.

Mary Clark: As former Director of an agency called Hearing Loss Link, we teamed up with Tom's RRTC and provided a late deafened retreat for late-deafened people in the Chicago area as well as another one in the San Diego area. I want to tell you how we set that up. We had approximately 25 participants at both retreats. What we try to do is ask a person to come and bring a family member. This is really important, because the hearing family member needs to learn about new coping skills as well as the person who is going through the transition of becoming deaf.

It is important to catch people, if you can, during the transition of becoming deaf so that they can learn coping skills and strategies and move on with their lives. Some people also come who know that their hearing loss is progressive and can then plan for their future.

Lack of access to resources is a big issue. There are many people who live in areas where there is no one knowledgeable about deafness and no other deaf people to connect with. If they are not on the Internet, they have no support at all. These are the people that can really benefit from retreats.

Identity is a big issue. Newly deafened people may have a lot of trouble figuring out what they are or who they are, and how to describe themselves. It can be a big struggle. The

people at these retreats usually range in age from 25 to 70, but I have seen 85-year-old people come and benefit also. What is mainly needed, is a willingness to learn new coping skills. When people come to the retreats they are often a little bit resistant because of anger at what has happened to them, but, by the end of the retreat, they are willing to go home and put new skills to work. It is very helpful for one supportive family member to also attend, as hopefully that person will go back to their home and teach the rest of the family what they have learned.

(transparencies related to retreat activities)

Audience Member: What is the definition of recently deafened?

Mary Clark: I think we have to look at this as more of a transition rather than specific time period. There were some people that I have worked with that are late deafened that have been deaf 25 years and, and they still have not made that effort to learn coping skills and move on. So, they still consider themselves recently deafened, even though it's been 25 years.

At the retreats we demonstrate technology that might help. We talk about emotional and physical health and communication strategies. At times we break up into groups where all the hearing people(spouses and/or significant others) are together, and all the deafened people are together. It's funny, because deafened people are thinking: What are "THEY" talking about? And the hearing people are thinking: What are "THEY" talking about? And we never find out. It's a good way for people to be feel free to express themselves, because the hearing partner also has a lot of frustrations, even as the late deafened person experiences their own personal grief.

We do try to get an audiologist to come. It's amazing to me that a lot of people don't know how to interpret their audiogram. Family members don't know what the audiogram means either. The late deafened person doesn't know, and may not even be able to hear the audiologist's explanation. It would be wonderful if we could do all of this with CART (Communication Access Realtime Translation ) at the audiologists office so that all family members could read exactly what is going on at the same time. Unfortunately, that is never the case. We do discuss the audiograms with CART present at the retreats.

We also provide information on CIs, though it is important to work through the grief of the loss first. We talk a lot about grief and try to get the hearing family members to understand what it means to lose your hearing—how it disconnects you from the world. That can be very powerful. We do an activity where we divide into groups and each group puts on a skit that shows a good way of communicating and a bad way of communicating. The groups are mixed with hearing and late deafened people. And there is no CART, so each group has to figure out how to communicate with each other.

At the end of the retreat we have a panel of people that have experience with hearing loss, and we ask for questions from the audience. We get some really good questions, because by the end of the retreat everybody feels safe with each other and is not hesitant to ask anything.

The general timetable is as follows: On Friday, everyone checks in and is introduced and we have a general session where we talk about deafness. We have an assistive technology workshop shortly afterwards. Dealers are invited with examples of their wares so that people can actually try assistive technology out. We always eat our meals together. This can be hard on our first night which is Friday when people don't know each other well, but by Sunday everyone wants to sit together.

And no matter where we go to hold the retreats we try to find people knowledgeable about the resources in that particular geographical area.

The Saturday schedule is always hard with so much to cover both technically and emotionally so by dinnertime people are exhausted. But then we do the skits, which somehow revives us all. On Sunday we often do what's called meditation techniques. It is calming and an excellent stress reducer. Then comes the panel and we wrap up and leave by noon.

Jeanne has a lot to add related to personal things that add to the retreat experience.....

Jeanne Naglewski: I have had a hearing loss since I was five years old. I went through the school system. It was rough. Why would I choose to go to a retreat weekend? I had never really looked at myself-- and my husband had never met another male that had a wife who was hearing challenged. Now at the time I was pretty sophisticated technologically. When I went to the retreat, at first we all sat there prim and proper. There was a young man, 22, and his father. The young man had gone to a rock concert about six months before and three days after the rock concert, he was deaf. He was having a very, very difficult adjustment. His father really thought that, if he wanted to, he could hear. And the son was trying to date and do normal things and couldn't because he couldn't hear. The father was a very technology-oriented person, full of suggestions. This boy had a broken heart. He sat there, and when he was asked how he felt about losing his hearing he said: "I feel castrated." His father didn't say a word. "All My skills that I have learned in 22 years are lost. I knew how to talk to girls, I knew how to charm them, but now, they don't know sign, where do I go? Where do I fit in?" He didn't feel he fit in with his family. Another young couple were there, and the mother had lost her hearing. She had three young children. She wondered, how are they going to feel when they grow up? Are they going to be proud of their mother? Are they going to say: "I really don't know her?"

Hearing these things hurt, for I have a genetic progressive loss. My mother had my loss and I have a young daughter, my first child of three, who has my loss. And I wondered, looking at this young couple, how do you figure this out? Where do you go to get these answers? And the more we talked as the weekend progressed with Mary's itinerary of workshops, we learned from each other. That Sunday, the father of the young man, who wasn't a verbal person, said, "I never had a clue what my son was going through." And he was wiping his eyes. These are the kinds of things that happen when you bring people together and ask them to share. We all need support systems and only by sharing can we get them. So, when you sit next to people, give them the benefit of your love in your heart, because they are sitting there, waiting. They are perhaps hurting, and if you can share, I think that's the biggest gift of the retreat: The people opening their hearts to one another, taking a risk and saying: "This is me, this is how I feel."

Retreat Attendee: The retreat was important to me, and my family for a number of reasons. It was important because my husband could talk to other people who are in the same situation. He often feels like the forgotten person and it's hard for him, too. I was very disappointed Friday night because I had heard you go to these meetings and can understand people and can communicate.

It is kind of dumb, but I thought I was going to be in a group and suddenly be able to hear. I am a shy person and when I couldn't understand at the table, I didn't put forth any effort. But at the end of the workshop my heart was touched. The grief workshop was wonderful for both my husband and I. Sometimes it is the small things that make a difference in a person's life. I can remember standing with Tom, and he signed to me that life would get better. I don't know why, but I believed him. We can all touch people's lives like that, without even realizing it.

Tom Goulder: There are two things that have happened within this last decade that are so significant that they are going to turn the whole culture of hearing loss upside down. The first is the technology of the cochlear implants. What I'm seeing in the world with pre-schoolers is the most amazing thing I have seen in education in my whole life in this field. The thing I am seeing with the pre schoolers who we have graduating from our auditory oral programs in California, is that when they go from the kindergarten to the first grade in public school, their language ability is the same as hearing children. And kids who are in second and third grade are at the same reading levels the hearing children. That we never thought would happen. I still work at the California School for the Deaf, and the high school seniors, those that were born deaf and were not implanted still have a fourth grade reading level.

The second thing we thought would never happen was early identification of hearing loss. Prior to this time we were failing to identify hearing loss until the child was on average three years of age. Now, with the passage of universal screening and hearing detection laws, we are identifying children who have a hearing loss within 30 days of birth or less. This is changing the whole field of education and the language development and many of these kids because of early identification and intervention are reading at grade level.

Implantee: I think it's important that you know that I am a CODA--a Child Of a Deaf Adult; my mother is deaf. So, I was raised in a culturally diverse family where sign language was really my first language, but I also had enough hearing to learn English naturally. As I grew up, my hearing loss progressed. I was pretty severely hard of hearing when I was 18 and then I lost my hearing during my pregnancy. But during the periods of 18 to 25 I managed and graduated from college without any interpreter services, and did the best I could. I am a person that if you tell me I can't do it, I will try to do it anyway. But nothing prepared me to become deafened. One morning I rolled out of bed and I couldn't hear anymore. I thought I was dying, and that period when I was first diagnosed with deafness was a black tunnel. I thought my life was over. My profession certainly was. I was a marketing agent for a large computer firm. My husband, who was hearing, couldn't identify with me anymore and we ended up getting a divorce. My son, who was born hard of hearing, and that was my fault, too, because genetic loss was in my family. My whole world seemed to be coming to an end.

Now even at this point I did not identify myself as a deaf person. So, when my mother said: "Go to a deaf agency," I said, "But, mom, I'm not deaf." It took me a long time to identify the fact that I was deaf. I was just living in a black tunnel of denial. But there is light to be found at the ends of tunnels. It took me 8 years to find it. Fortunately, thanks to the technology that we have today, the computer, the Internet, this is a good time in history to be deaf. And this is why I am active with ALDA and I travel across the country giving presentations on hearing loss and deafness and cochlear implants.

Cochlear implants are a very, very touchy subject. When I went to my mother and said: "Mom, I am going to have a cochlear implant," she said: "My god, what will my Deaf friends say?" So, we had a culture difference. I have had my implant now for nine years and, my mother has been able to see what I can do and she no longer feels that way.

I am a poster child for implants, but it doesn't work the same for everyone. This is why Tom and I decided to do is go out and look at the diversity of people with implants. We knew that there were professionals who have to provide services to cochlear implant recipients but didn't know how. We, as professionals, need to provided services and information to those who need them—professionals, parents and recipients themselves. So Tom and I travel far and wide to give honest and truthful information. It's still a new and uncharted territory.

Tom Goulder: There is still much to be done in regard to hearing loss and in regard to claiming our identities. One of the things that has always struck me about hearing loss, particularly with late deafened individuals, is what Dr Harvey was talking about this morning: The transition time in terms of who we are now to who we will become after losing our hearing. Answering this question is very important. I think that each one of us has our destiny and our dream of what we would like to do with our lives. And if you get hit with a hearing loss, perhaps your cart was upset and your dreams sort of vanished and disappeared. But I believe that nothing is coincidence. I have dyslexia as does my mother, and when I was in the third grade, I would sit at the table and cry because I couldn't read. My mother helped me by using wood blocks that had letters on them. I learned to read using my hands. Now, that was a disability. It set me back. However, by determination, I have been able to do everything I have set out to do. My disability hasn't gone away, but I have learned to compensate for it. This disability brought me into deafness, because I was taking a language course in college and I was failing the course, and friends of mine said: "Hey, you know you can get college credit for sign language." So, I took the sign language course, because I was failing the spoken language course. Guess what? I was a natural signer. It was so easy for me, and my teacher told me I should be in this business. And I have been in this business ever since.

We so often think that something that has happened to us that is bad. I believe that nothing that we were born with-- or the conditions that come to us are really meant to harm us. They have a way of bringing us to other people and connecting us with other people that are meant to be. Now we have cochlear implants, and TTYs and computers and science is moving us right along. I believe that science is God's gift to us, and as I look at the world and dream of what I want to do in these closing days of my professional career, I realize that what I want to do is to fulfill a dream that we had ten years ago in the field of deafness—and that is to set up centers where families can come and learn about hearing loss. I am on my way to setting up just such a center. Nothing is a coincidence.

I will give you another example. It occurred to me while meditating that there was someone who could help me with my dream of setting up such a center in Idaho: Ted Turner. He has got lots of money and is interested in land and preservation of the natural. Three days later I was at a friend's house and I met the wife of an engineer, who told me her brother-in-law lives in Boise and could probably help with me this center. And her other brother-in-law is the property manager for Ted Turner's properties around the world. Now, I didn't plan this. Perhaps our lives are like a CD-ROM you put it in the machine and it plays out. You can't see it happening but it is happening and you just have to open your mind and your heart and follow the disk. Each one of us has a dream, a vision-- something you need to do in the world that nobody else can do. Nobody else can do it. So, you can't let dyslexia, a broken leg, old age, hearing loss, stop you from fulfilling your dreams. Go with your dream. Thank you.

Dr T. Jordan Goulder has worked in the field of hearing loss for 42 years. During this time he has witnessed significant changes within the world of hearing loss. He is recognized for establishing the state/federal/private Mental Health programs for adults and children with hearing loss. He currently serves as Director of Training for the RRTC San Diego, CA, and is in the process of establishing an Auditory-Oral teachers training program to be located at National University, San Diego.

Mary Clark, who lost her hearing 13 years ago, is a private consultant specializing in counseling orientation and education for those who are late deafened. She is a graduate of Ball State University and holds a degree in deaf education. She is former director of Hearing Loss Link, the only agency in the country, which exclusively serves the late deafened. She has facilitated and presented late-deafened retreats sponsored by organizations including the Steve Hodges Foundation in Austin, Texas and the California School for Professional Psychology San Diego, CA. She is involved in many local, regional and national boards and committees and has served in various capacities for ALDA Inc. She is currently President of ALDA.

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Goulder, T., Clark, M., & Naglewski, J. (2003). A Theory of Everything about Deafness. In L. Piper & D. Watson (Eds.), *Selected proceedings of 2002 conference of the Association of Late-Deafened Adults*. [on-line] available: <http://www.alda.org/aldapubs.htm> and <http://www.uark.edu/deafrtc/publications.html>