

A CELEBRATION OF DIFFERENCES

Ruth Moore
Jonathan O'Dell

RUTH MOORE: I work as the communication access-training specialist for the Massachusetts Commission for the Deaf and Hard of Hearing. And Jonathan O'Dell is the director of the Communication Access Training and Technology Services Department. When I was a teacher of the Deaf I had a placard that said, "Ruth Moore from the Willie Ross School for the Death." They misspelled Deaf as death. We're going to be telling you some stories from our personal lives like that.

JONATHAN O'DELL: I talked to some people yesterday, and I told them what this presentation was going to be about, and they said they'd bring plenty of eggs and vegetables to throw at us. Please check them at the door. We'll make omelets afterwards. We are going to be talking today about some of our own personally held views, based on some of our personal life experiences.

RUTH MOORE: Both Jon and I are deaf. When he was born he could hear. I was born deaf. My parents did not realize that I was deaf until I was about 18 months old, and they were calling my name, and I had my back to them, and I wasn't responding. When they found out my parents were just totally at a loss of what to do. They just had no idea of how to manage the situation, and went through a grieving process. It took them a while to be able to return to a normal life. They got a lot of support from their friends and they realized eventually that everything was going to be okay.

I went to a specialized school for the Deaf that focused on oral training, and on speech reading. I was very frustrated, but I didn't give up. My parents were very encouraging and after I finished at school, I went on to Gallaudet University, there I took a speech reading test, and I passed that with flying colors. Despite all my oral training I had learned some sign language from my friends, and when I was tested in that I failed the test. I had to take a sign language class for to learn the proper signs.

At Gallaudet, I met a deaf man. The two of us fell in love while we were there. On graduation day, we flew home and got married that evening, and people thought we were absolutely crazy. We are still married today after 39 years. We have two happy and healthy boys both of whom are deaf also. One of them married a deaf woman and they have two hearing but bilingual sons. My other son married a woman who could hear. I never dreamed that he would do that. But she's a sign language interpreter, and they're able to effectively communicate with one another, though they do have some cultural differences. They have no kids, but 12 pets.

JONATHAN O'DELL: I grew up in Vienna, Austria, and German was my first language. When I was about nine and a half, I got the measles and then meningitis which caused me to lose my hearing very rapidly in about 3 days time. I was at that time enrolled in the American International School, where English was spoken, but was forced to transfer to the German-speaking school for the hard of hearing, which was oral, no sign language allowed. But we did use rudimentary signs behind the teachers back of course. It was not a sign language but a European alphabet. I did so well at school, that my father thought I would be able to make it in a "hearing" school. At that time, there were no mainstream programs that offered any support services for children with hearing loss whatsoever. I was eventually sent to England to a private boarding school where I was the first, and probably the last, hard of hearing person who went there. At that time, I considered myself to be hard of hearing, because I could speak reasonably well on the telephone. I've lost that ability now. I was a very, very angry person. I had lost my hearing. My parents had moved. My father moved to Africa, and my mother to Germany, so I was in England by myself, surrounded by hearing people and feeling terribly isolated. Somehow, and I have no idea how. I managed to graduate from that school, after which my father sent me to a school in Wisconsin in this country. I don't want to talk about that. It was miserable. Everything was lecture-based, and I understood nothing. There were no support services. At that point I did not even know what an interpreter was. I didn't even know there were other hard of hearing people. I thought the only other hard of hearing people in the whole world were the people I had met in Austria. After four years I was basically kicked out of college, the same one, by the way which also kicked out the actor Harrison Ford. I'm still waiting for Hollywood to discover me.

After that I kind of did odd jobs, fell in love with a woman, and moved to Boston, where I found my first professional job at an independent living center, counseling other people on how to live independently, that's one thing I was good at, having been independent since the age of 13. Slowly I managed to work my way to where I am today, in a variety of different capacities. Today I work for the Commission for the Deaf and Hard of Hearing.

I consider myself to be a situational late-deafened person, and what I mean by that is that I don't like the fact that sometimes we get labeled and these labels stick to us, and we say this person is hard of hearing, this person is late-deaf, this person is deaf. What I am is I am a situational person. In some situations, I function fine one on one. I usually don't have any problems in an intimate conversational setting, but you put me into a larger group, add background noise, the room getting dark, someone with an unfamiliar accent, and I am lost. I need to have CART. Listening systems alone doesn't work for me anymore. It amplifies only. I can hear but not understand. So then, I become situationally late-deafened. Even after all these years both Ruth and I are finding out new things about how we feel about our hearing loss everyday. There is a lot of animosity sometimes between the different groups of people with hearing loss. And I think -- and I think Ruth believes it also -- that this is due to people not really understanding what's going on here. They don't really understand. How many hard of hearing people understand Deaf culture? How many people who are in the Deaf community understand what it means to be late deafened? And so, in this workshop I intended as a little bit of a dialogue about these things and share some of the ideas that we've come up with.

RUTH MOORE: My first years at Gallaudet were not easy because at that time, a lot of deaf people did not use their mouth a lot when they signed. Their hands conveyed everything. I have slowly become less oral over the years, despite my early oral training, and can function in the Deaf community and use American Sign Language. Now most culturally Deaf people are born Deaf and usually use ASL and have been to a school for the Deaf. They might use gesture and mime, which incorporates a lot of use of facial expression, which makes up for the inability to hear vocal inflection. Hearing people very often have very little affect or expression on their face because it's all carried through their vocal inflection. Deaf people make up with that with a lot of facial expressions for happiness or being sad. Sometimes -- some people might think, geez, deaf people over do it, but that is part of the culture. Some Deaf people choose to use their voice. Some will just use sign language. Their fluency may vary in written and spoken English, and some rely on paper and pen as a last resort to avoid misunderstandings. They may or may not be involved in the Deaf community in advocacy or social events or deaf clubs.

JONATHAN O'Dell: Now, a late-deafened person usually has a post-lingual hearing loss. And that they will of course continue to use spoken English. Some people ask me how come late-deafened people continue to speak English. Most people don't decide, hey, I know that I'm going to lose my hearing next Wednesday, so I'm going to learn sign language today. It doesn't happen like that. You lose your hearing all of a sudden, very traumatically, as happened with me, and you find yourself without a way to communicate, so obviously you are going to continue to speak and continue to use that method of communication.

Eventually, most late-deafened people, I believe, will learn some form of sign language. Some people will learn ASL, but relatively few. Most people end up learning signed English, and doing pretty well with it. As I said before, I do tend to use CART in complex situations, and the complexity of the situation can be caused by background noise, it can be caused by distance, it can be caused by somebody being so far away I can't lip-read them anymore, or any of a number of other things. I also use paper and pen as a last resort. Most late-deafened people continue to function in the quote, unquote -- "hearing world".

RUTH MOORE: People who are born deaf, who have Deaf parents and are raised in an environment where they use American Sign language, tend to identify with the Deaf culture. So when you see the word "Deaf," we tend to use that with a capital D, which refers to a culturally deaf individual.

JONATHAN O'DELL: People born hearing to hearing parents and who use spoken language to communicate before they lost their hearing, deaf means something entirely different. To them it has a medical, audiological context, as a loss of hearing. One thing we're talking about here is semantics and this is important as it causes a lot of people a lot of frustration. The hearing world, generally tends to view hard of hearing, late-deafened and deaf people as being dysfunctional, meaning that they cannot hear anymore and that situation is seen as a limitation, and a barrier and a problem and disability. They have what we call the pathological view of hearing loss.

When I entered the Deaf world my problem was precisely the semantics issue. I came over from Europe, and was very isolated for, I would say, probably eight years or so. I was the only hard of hearing person I met. It was pretty sad. At 24 I found out about closed captioning, bought myself a decoder and watched about 250 movies in the first week. I took time off from work and sat at home and watched one movie after another movie after another movie. Then I found out about Deaf community, and I was like “yes!” People like me! All right! Wonderful! Awesome! So I went to a gathering at a local watering hole. Now, at this point I thought of myself as being deaf and was delighted to discover that there was a Deaf community. And I went there that night, and I got the shock of my life. These were not deaf people like deaf people I had ever imagined. These were people with hands flying. There was a roomful of people, and nobody was talking. There was dead silence, except for the loud speakers which were so loud you could feel the room shaking. But there was nobody talking. I understood nothing. I cannot tell you how shocked I was because I had thought to myself that these are people like myself. I felt I was finally going to fit in and obtain support. And to make matters worse, these people looked at me as being very different. They did not see me as being Deaf. Perhaps Ruth can explain how she as a Deaf person feels when someone approaches her and says “I am deaf.”

RUTH MOORE: In the past, when I first met a late-deafened person, I could not figure it out. They don't sign very well. They're not using ASL. Where are they from? That was about 10 years ago. But as I've come to learn more and more about late-deafened individuals and their communication needs, I've made adjustments, and reasonable accommodations. Someone was telling me they had a date with a deaf woman, and that deaf....

JONATHAN O'DELL: Let me admit here that I am that friend. I had a blind date with a Deaf woman, and at the end of it she gave me a passionate, long, drawn-out hug. And two days later, I saw Ruth at a presentation. I was grinning from one ear to the other and told her about it. She smiled, didn't say anything. Then she did a presentation with me, and somewhere in the middle of the presentation, she says, "Oh, in Deaf culture, everybody always hugs everybody." I was heartbroken. I had thought I was getting a passionate hug when it was simply Deaf culture at work. I don't think I understand Deaf culture. I still don't. Half of the time, my opinion used to be -- used to be -- that it was an excuse for bad behavior. And that was because I really did not understand what Deaf culture was about. We all have, to some extent, the same name. We are all deaf and have no hearing. But there's a huge chasm between being Deaf and late deafened, and if you don't know about that, it can get you into real trouble.

My first response from the Deaf community was hurtful. I had unrealistic expectations. I had thought I was going to be embraced with open arms, and I wasn't. I was an outsider. I was more an outsider in the Deaf world than I was in the hearing world. And it was a very, very unpleasant time for me. I became very, very upset. I could not understand why my own people were rejecting me.

RUTH MOORE: I understand how you feel, because I didn't really realize that I was Deaf until I was ten years old. No one had ever told me as I was growing up. And at the age of 10 a social worker at our school for the Deaf mentioned that we were all deaf and that we couldn't hear. I was actually shocked and very confused, and at first I was

heartbroken. It was only when I went to Gallaudet University and started meeting other Deaf people who communicated in sign language, and that I really began to accept my deafness.

Jon's situation is quite different than mine, because he had the experience of hearing as a child. I never did, and I'm wondering how that feels, Jon.

JONATHAN O'DELL: The thing that really puzzled me at the beginning was I felt so stuck. I felt like, I wasn't hearing enough to be hearing and I wasn't deaf enough to be Deaf. And that's a very confusing place to be. Not knowing where you belong. Fortunately, I was able to pretty much get through that, because I have a pretty strong sense of identity, but it wasn't an easy or enjoyable thing to go through. It would have been a lot easier if open arms by the people who I perceived to be deaf would have accepted me. Interestingly I married a Deaf woman, and it's interesting, that we have never really had those kinds of issues between us. I also had the bad fortune to run into less than welcoming Deaf individuals. Professional, educated Deaf people have always been pretty welcoming to me. I think it has something to do with the educational level and open mindedness. I also feel I have a stronger connection to older generations simply because at that time ASL education hadn't kicked in yet. Ruth and I, for example, both understand speech and the importance of finding a common ground.

Recently I went to a technology exposition and I saw a group of young Deaf teenagers signing a mile a minute. They were signing so fast I had no idea what they were saying. And that worries me a little bit, because while it's great for people to have that, I'm also worried, what it means for the relationship between late-deafened people, hard of hearing people, and people who are being brought up to see ASL and deaf pride as a way of life. That scares me a little bit, because I see that as something which will divide us further instead of bringing us together to get the support we could get if we were to speak with one voice and be seen as one interest group.

Another problem I had to deal with is that when I came to the Commission for the Deaf and Hard of Hearing I found they knew nothing, and I mean nothing, about the needs of the hard of hearing population. Everything was set up for Deaf people. And I resented that. Now I realize, it was a stupid response of mine, because it was Deaf people, culturally Deaf people, who have fought to get recognition for hearing loss, and who set up these commissions and organizations and the state associations for the Deaf and the National Association for the Deaf. This was all due to their efforts. And we, late-deafened folks, are, if you will, still emerging as a population, and only recently starting to come into our own rights. And I think in some ways we need to become more active and become more involved so we can get together and have a larger population base from which to work from.

RUTH MOORE: I would like to add something in terms of late deafened and hard of hearing people and Deaf people. When we get together we tend to segregate ourselves. At my parent's house on holidays at first we will all be communicating together in one way or another, but then, after a while, those who are Deaf will be at one end of the table signing and those who can hear at the other speaking. And I am in the middle. And I'm just wondering how we

can resolve this issue? It is very common and I saw the same thing at Gallaudet where the native ASL speakers tend to group together and those who have been raised in a more oral tradition, and speak and use signed English, group together.

We're talking about communication preferences. Some of us are more comfortable using ASL. Some of us are more comfortable writing back and forth. Some of us are more comfortable signing and talking at the same time. Others are more comfortable just speaking, and I think when we say "communication preferences," what we mean is respecting each other's differences.

JONATHAN O'DELL: There is a trend these days that is happening in marketing, which is which is specialization. You can, go to the Internet, and you can customize the news that you get to match your preferences. You can get just the information you are interested in, and this scares the hell out of me, because we need to understand each other, and you don't understand someone else's viewpoints if all you get is news and information that agrees with what you believe and know. I am at the Communication Access Department at the commission, and the one thing I will refuse to do is if somebody asks me, "I want you to give a presentation on Deaf Culture and American sign language," I will say: "No, we will not do that. We will give you a presentation on deafness and sign language and hearing loss and other methods of communication, but we will not simply give you a presentation about sign language or Deaf culture." And the same is true for the hard-of-hearing people because I think the more specialized you get in some ways, the more you cut yourself off from other people. And I think that that is just what has been happening to some extent in the organizations that we've formed. It is important that we understand one another. Deaf people must come to an Association of late-deafened adults meeting. Late-deafened adults must go to the National Association for the Deaf or equivalent state-level meeting.

Let's talk a bit about how we can learn from each other. Step one: appreciation. We have to appreciate and respect one another.

RUTH MOORE: Not only do we need to respect each other, but it's also important to learn from one another and educate each other. What does it mean to be a late-deafened adult? What does it mean to be Deaf? We need to accept who we are as individuals, and remember that we are people first, late-deafened or Deaf second. We're hard of hearing or Deaf, but we're people first.

JONATHAN O'DELL: One thing my wife taught me is that understanding is not always possible. I can never really understand what Ruth went through in her life. She can say it to me 150,000 times. I will still not understand. I can respect it, I can accept it, but I will not understand it. A culturally Deaf person looking at me as a late-deafened person, you will never understand what it's like to speak German, to hear German, to have your hearing, to lose it, to be embarrassed if you have a hearing loss. To be ashamed to have a hearing loss and struggle with those kinds of feelings. That's okay. We don't need to understand it. We need to accept it.

And we need to appreciate each other's accomplishments. Sometimes hard of hearing people will tell me that they resent that all the programs seem to be for Deaf people. Well, you know what? Without Deaf people we wouldn't be here. If Deaf people had not taught us how it is possible to advocate for our needs and for our services, most of us wouldn't be where we are today. I know I wouldn't be. So even though I'm not culturally Deaf I owe a debt of gratitude to culturally Deaf people because they showed us what is possible and we learned from them.

RUTH MOORE: It's important to support each other's perspectives. We're in a hearing world. We can understand each other. It's important that they understand who we are. Culturally Deaf people never know what it's like to have heard. Or vice versa. So it is important to keep our minds open, to learn from each other and to share with each other.

Jonathan O'DELL: And, if it's absolutely necessary that we all band together against the preconceptions and misunderstandings that hearing people have about all of us, no matter whether we are Deaf, late-deafened or hard of hearing. We must work together.

I was at the banquet yesterday, where the number was thrown out that there are 22 million people with hearing loss in the United States. First of all, that number is outdated and gone. It is more like 28 million people, and one wonders why with that many of us we have no power at all, compared to some other groups which are much smaller but have learned to speak with a single voice. We still don't do that and we need to do that. We have to come together and work together. We have to respect one another and advocate for one another. We have to remember that this is, above all, a hearing world. And we have to remember that it is more important to convince the hearing world of our joint needs than each other of our separate needs.

RUTH MOORE: We must respect and accommodate each other's communication preferences. Well, hey, you know, let's try to understand each other. Let's try to communicate with each other. That's the key. Open up. Open your minds to the world. Share your backgrounds with one another. Talk to each other.

A Deaf person will ask you first where you went to school. Where are you from? Who's in your family. Where do you work? And then make an introduction with a name at the end. Whereas, a hard-of-hearing person or late-deafened person right away will ask you your name. And then they'll ask you anything about yourself. So you'll notice those different approaches. And this is diversity, and we need to understand that.

Learn too about the resources out there; the services; the different organizations. You meet someone who's late deafened and they may know nothing about ALDA. Well, if I know about the organization, why don't I pass that along to them? We need to share these resources and share these opportunities so we can be supportive of one another.

JONATHAN O'DELL: We also have to be very observant of what's going on in terms of technology, because a lot of the new technology is moving away from things that are helpful to us, and moving more towards voice recognition, and that's frightening. Because what's happening now is we're going back to the bad old world where everything depends on voice and listening, and I don't like that at all. The more of this stuff that comes out the less we benefit. We have to start working together to put pressure on people to do things the way we want them to be done, not an afterthought or after-market approach, but before we see the technology hitting the market. Technology can actually take away our access and we must be on guard, together, against that. For example, television, in the beginning, the regulation for digital television that was proposed, would have done away with closed captioning. I don't call that progress. You get a better picture but have no more closed captioning. I don't call that progress. But with pressure committees met and found a solution.

RUTH MOORE: We can advocate together, and for one another. Work together. Teamwork. Think of each other. Communication access is so critical and so important to all of us.

One way to do this since there are really so many people who have hearing loss would be through political action. But the problem is, so many people with a hearing loss do not admit that they have a hearing loss. On average it takes them about seven years before they even begin to think about asking for help. So it takes a lot of education, as we have found in Massachusetts, to get people to the point where they even recognize their needs, let alone are able to advocate for themselves.

JONATHAN O'DELL: I want to give you a last parting shot at how difficult it can be sometimes to make everyone happy. The commission has recently designed a poster to basically raise awareness of hearing loss and we ran that poster very successfully in the MBTA, which is the Massachusetts Bay Transit Authority in Boston. It was very successful there, and we also recently handed out 60 or 70 of those posters through the Council Of Aging Directors. And I thought, this is going great. And one of my Deaf colleagues who is culturally Deaf comes into the office and says to me, "I don't like that." I'm like, "What are you talking about?" And she said: "This poster is an insult to Deaf people." I thought, "Here we go again." The poster says, "Hearing loss shouldn't slow you down, " and Deaf people don't see themselves as having a hearing loss. On the other hand, if you said deafness doesn't slow you down, then hard of hearing people might find it offensive. So it can seem like a no win kind of situation, and we need to stop this nonsense.

Ruth Moore was born deaf and has a B.S. degree from Gallaudet University in Washington, and a M.E.D. from Smith College in Northampton, Massachusetts.

Jonathan O'Dell lost his hearing from spinal meningitis at the age of nine and became late deafened as an adult. He has a bachelors' degree from Harvard University in Boston.

MCDHH.webmaster@state.ma.us and their website URL: www.state.ma.us/mcdhh

