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Patient Stories and The Role of The Audiologist As Listener in Hearing Loss Treatment

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## Patient Stories And The Role of Audiologist as Listener in Hearing Loss Treatment

### Panelist Question Set

The original format for this presentation was planned as a group discussion with the Aural Rehabilitation Social Worker, Cathy Kooser, participating as facilitator. Because Ms. Kooser was not able to attend the Institute, the panelists have each developed their stories as a narrative in response to 5 question prompts:

1. What do you experience as the worst thing about hearing loss? *(This is a prompt used in aural rehabilitation group therapy and comes from the work of Rehabilitation Counselor, Anthony Hogan.)*
2. Of all of the challenges that hearing loss has presented to you in your life, is there one event or crisis that stands out as having been the most difficult for you? How did that difficulty affect your ability to participate, and how did it affect you emotionally?
3. Was the challenge that you described eventually resolved, or has it persisted? What resources have you found to help you cope with this difficulty?
4. Are there aspects of hearing loss that affect your ability to participate in areas of your life that are important to you? Are there physical or emotional repercussions of those restrictions that concern you?
5. In receiving hearing health care, what qualities do you think you most need from the professionals who provide your audiologic care?

## Introduction: Peggy Ellertsen

*[Peggy Ellertsen earned the Certificate of Clinical Competence (Speech/Language Pathology) from the American Speech-Language-Hearing Association in 1971, and a Certificate of Advanced Study in Reading and Human Development from Harvard University Graduate School of Education in 1979. She has worked as a Speech/Language Pathologist and Reading and Language Specialist in clinic, public school and private practice settings for over thirty years. In 2011, she became a Certified Peer Mentor for Hearing Loss through the professional certificate program at Gallaudet University, and continues to learn about best practices in aural rehabilitation through ASHA's Special Interest Group 7, The Academy of Rehabilitative Audiology and the Ida Institute. Peggy currently serves on the steering committee for Hear@Boston, HLAA's Boston chapter, and coordinates the chapter's speaker program and its outreach initiative to audiology practices. She consults to persons with hearing loss around active management of communication through the use of assistive technologies and communication strategies.]*

I trained as a speech language pathologist and reading specialist, and have practiced in public school, clinic and private practice settings. I have a severe, progressive, sensori-neural hearing loss and currently practice as a hearing loss management coach for persons with hearing loss. And so I wear two hats: one as professional, and one as hearing loss patient.

My interest in the use of patient stories in hearing health care began from a consumer perspective, and has grown as I've learned about best practices in aural rehabilitation. My appreciation of the value of audiologists listening to their patients' stories was consolidated when I studied with Dr. Matthew Bakke and his graduate students at Gallaudet University in the Peer Mentoring for Hearing Loss program, the extraordinary aural rehabilitation training program originally envisioned by Dr. Bakke and Drs. Scott Bally and Mark Ross.

When I arrived on the Gallaudet campus in the fall of 2008 for my orientation session, I brought my audiogram with me, as had been requested. My new classmates and I spent some time during our first morning together examining each others' audiograms and sharing what we knew about interpreting patient audiograms, but most of the orientation session was spent with my classmates and me sharing with each other and with our instructors stories about our life's journeys with hearing loss. It was an extremely powerful experience for each of us, not only

because we were given an opportunity to talk with candor and in depth about this central struggle in our lives, but, more importantly because, as we did so, the audiologists who were to be our instructors over the next two years listened with such rapt attention.

During our two years of study, my classmates and I both examined the audiograms of many people with hearing loss, and we also read extensive accounts of patient stories that were contained in detailed case histories. We were encouraged to use these as important resources for recognizing and understanding several important factors. These included:

- differences in individual patient treatment preferences;
- the impact of life events – especially previous traumatic loss - on the individual's rate and style of adaptation to hearing loss treatment;
- the presence of possible emotional and physical stressors as a result of living with the challenges of hearing loss, as well as patient strengths in coping with and adapting to hearing loss;
- importantly, specific participation restrictions of individual persons that, for one reason or another, had either been addressed superficially in treatment, or had not yet been identified or addressed at all.
- Finally, we were encouraged to think about possible technical and non-technical options beyond hearing aids and cochlear implants for helping people resolve some of the specific, unaddressed difficulties that were revealed in their stories.

I would like to briefly point out to you the list of references in your packets. This is only a modest sample of some of the exciting literature on patient centered hearing health care and the use of the patient narrative as an important resource for creating a treatment plan that optimizes adherence to recommendations. Especially relevant to today's discussion is the investigation of

a model of shared decision making by Drs. Louise Hickson, Arienne LaPlante-Levesque and Linda Worall. Their research reveals important insights about the significance of the use of the patient's story in terms of the patient's perception of his/her treatment, and the impact that the use of the patient's story has on the development of trust in the encounter between patient and audiologist.

As we begin, I'd like to draw your attention to three copies of a needs assessment which are included in your packet to help you structure your thinking as you listen to each of the panelists' narratives.

#### Patient Story: Tram Lai

*[Tram Lai immigrated to the United States from Vietnam with her family when she was nine years old and began to acquire English as her second language. She experienced sudden, profound hearing loss when she was in her mid teens. In 1997, two years after receiving her cochlear implant, Tram was awarded multiple scholarships, including the Boston Guild for The Deaf and Hard of Hearing Scholarship, and studied Environmental Science at Suffolk University in Boston, where she earned her Bachelor of Science Degree in 2002. In 2011, Tram earned a Master's Degree in Public Administration from Suffolk. Currently, Tram is the Laboratory Manager in the Department of Chemistry at Suffolk. She was recently recognized as the 2012 Outstanding Young Adult by the Hearing Loss Association of America.]*

Good evening, everyone, my name is Tram Lai. When I was in my mid-teen, within a period of one week, I lost all of my hearing in both of my ears. During my junior year in high school I got a cochlear implant.

I believe the worst part of losing my hearing was losing hope along with my hearing. I was a young teenager full of dreams and hope for my future. The day when the doctors told me that I will never regain my hearing, I felt that all my dreams and hopes were gone. My bright future was gone before my eyes. Maybe to other people this would not be the end of the world, but to me was it the end of my world. There was not a light at the end of the tunnel for me. My bright and beautiful world was now filled with pain, sadness, and loneliness. My family didn't

understand what I was going through because they had never encountered this illness before.

When I was able to hear, to me the “guessing game” was fun. But now that I can no longer hear, the guessing game to me is no longer FUN! For two years of my life the only way I could communicate with people was through writing.

There has not been one specific worst crisis, but rather an ongoing set of problems that I’ve had to face. As a person living with hearing loss, waking up in the morning, I like to boil my water in the kettle to make tea so that I could do offering to my ancestors. I usually boil the water before I put on my external device. Then I get ready for work, and sometimes I forget about it. My family thinks that I am going to burn down the house one day because I can’t hear the kettle and the smoke detector going off. If there were someone at the door knocking and telling me that my house is on fire I wouldn’t even know it.

Another problem would be that I am very nervous at work when I have to pick up the phone or I have to call other than my friends.

I resolved my problems with anxiety and worry caused by hearing loss by working through them. I often invented my own solutions – For example, I remember back when I was in high school during the years that I was deaf, we have two teachers who are notes takers with us while we are in class to help us with note taking. Since I could not hear, and was shy, whenever I had to talk to a teacher, these teacher’s aids would talk to the teacher for me. I like it, but when I got into college, these teachers’ aides were no longer with me. I was in the real world. I was alone! There was a class I didn’t do very well but I need to know my grade from my final. I was scared! - too afraid to talk to my professor. But I keep on telling myself that I could do this, I have to do it. No one will do it for me. I went and talked to her and I got an A as my final grade. I felt so good afterward, not only because I got A for my grade, but because I finally broke

through another barrier that forced me to do something that I would have never done in the past if I had my teacher's aide with me.

A few months ago a friend of mine recommended that I should begin to utilize my T coil with a looping system or with an FM system. When I got my Freedom upgrade a few years ago this wire came with it, I tried it out with my friends and it has too much static, so I am discouraged from using it.

As for the phone, I trained myself to be confident by calling my friends. I try to talk to them on the phone as much as I can so that I can get used to listening to their voices. As times went by I became more comfortable picking up the phone. Once I got better at it, with my implant, I was able to tell the difference between voices. For example, if my friends Alena or Linda call and say "it's me" my brain will start scanning to figure out who I am talking to. Within a few minutes I can tell who I am talking to.

On June 19, of this year I went to a HLAA (Hearing Loss Association America) convention here in RI. They have a booth that was set up about caption call phone. It is free. They had a demo booth and I tested it by calling my boyfriend. I love it! I could hear most of what he was saying to me over the phone, but it was nice having the caption call subtitle available in this way so I know that I am 100% sure that I understood everything in our conversation.

There are areas of my life in which my ability to participate in certain activity has become limited because of my hearing loss. When I am with my friends, having our girl's night out at a restaurant, it can be very loud and hard for me to hear as we speak in multiple languages.

The people around me love to travel but I don't. The reason I don't like to travel is because I always worry that my implant might malfunction when I am in a foreign country. They

don't have the technology like we do. I haven't even stepped out of the house, and already I feel all this anxiety so traveling for me is a big NO NO!!

With my story, I would like audiologists, doctors, friends, to take with them. When I am at the audiologist office the services are great and I have their undivided attention. But when I go home with my new device, I feel a little lost. It would be helpful to get an email to check on how I am doing with it. For me, this is important but for other people, especially for older people, they might need more help than just an email in order for them to learn how to use their devices, walk them through it so they don't become frustrated. In one of my Health class, I studied that in the old days patients viewed their doctors like god. But this is the 21<sup>st</sup> century; I want to see my doctor as my partner. We explore the new technologies together.

#### Patient Story: Jim O'Donnell

*James F. O'Donnell practices law in Boston in the area of disability law, with emphasis on advocacy for children with disabilities in educational settings. Jim served as Massachusetts Deputy Commissioner for the Deaf and Hard of Hearing from 1999 to 2003 and subsequently worked as Special Education Administrator in the Boston Public Schools. Before initiating private practice, Jim was Executive Officer of the Boston Retirement Board and a member of the Commission for Persons with Disabilities. He has also worked as a specialist in employee benefits and taxes in private industry. Jim holds degrees from Suffolk University Law School and Simmons College, where he earned a Masters Degree in Special Education. In addition, he has served as a volunteer in leadership positions for a variety of non-profit organizations, including the Boston Guild for The Hard of Hearing, Association of Late Deafened Adults, and Hearing Loss Association of America. He currently is a member of the Steering Committee of HLAA's Boston chapter, Hear@Boston.*

I was born with a severe hearing loss and had to adapt early on by using a hearing aid, rely on my vision as an aid to read lips and constantly strategize on how to engage with people and communicate. The worst thing about hearing loss - there are many - is lack of directionality, that is I cannot tell where sound is coming from. I'll give you two examples from my experience which reoccur often: I am with a group of six or seven people in a coffee shop and people are kibitzing about this and that but I am falling behind, missing out on words, because I don't know

who just spoke. That means that I miss the first few words of someone's sentence and that usually contains the subject of the conversation. I get frustrated and try harder to get the gist or begin to ask questions. But asking questions draws attention to me and my hearing loss and that means embarrassment to me. I'll explain why that is in a minute. In a professional meeting, I can ask speakers one at a time with notice (raising hand) or the like but in a social setting, it's very difficult to ask for accommodation. This feels humiliating and depressing; I get down on myself although I know it's the lack of hearing and the environment, not me personally.

A second example: I am alone in the house or in the yard and I hear a sharp, loud noise. It prompts my attention, but I don't know where it's coming from. I don't know where to look and so I begin to check out everything. This is fearful to me - frightening in that I cannot tell what the sound is - is it a problem or a threat? Or where the sound is so I can't visually go and see what it is and whether it represents harm. My fear is that I do not know if I can protect myself.

The worst challenge I had was when I lost my mother at the age of ten: I had denied myself the reality of the sickness my mother had despite the obvious clues because I was so dependent on her as my communication link and supporter that I could not contemplate my existence without her around. So when she died, the news, the realization, was a huge shock to me. To cope, I fell back into denial and continued to deny that she was gone by believing that God would bring her back to me. Looking back, that seems absurd but I was desperately afraid and reached for any kind of comfort. Of course that did not happen, I became very angry - very angry at God and very angry with myself. I blamed myself as the cause of her death because I knew I was disabled and not being normal caused her leaving. I took this anger and became determined to prove I was as good as anyone else who's normal. This determination became a relentless drive to prove myself when given the opportunity.

This anger became a drive to prove myself and subsequently, I went to law school, practiced law at the corporate and tax level, and then achieved a lifelong goal to be an administrator in a government agency when I became the Director of the Boston Retirement Board for ten years. For the last eighteen years I have practiced law in the disability area in one form or another. I accomplished more than was expected of me because of this drive. I still have this drive although I don't need to any more since I retired from government but I still have a small law practice in disability law and do pro bono work in courts. I recognize the cost to me has been a constant amount of low level anxiety and a state of denial that made it very difficult to ask for accommodations even though I am an advocate for others. It was hard work.

Every time I am in a three person or more conversation, I miss things that are said: I miss the jokes and some of the information from others that flows in conversation. Every time I hear a song, I may enjoy the melody but I can't make out the words. When the phone rings, I let it go to message rather than pick up to avoid difficult conversations. This happens almost every day and sometimes several times a day. Because I still have this desire to be "normal" – unrealistic as it is - I do get frustrated when any of these instances occur. And I feel my personal worth becoming "dis-abled." It's a constant effort to keep a positive perspective on myself despite what I have been able to do.

### Patient Story: Candy Saunders

*Candy Saunders, LICSW, is an assistant clinical professor at Simmons College Graduate School of Social Work and coordinates its Post Graduate Clinical Certificate Programs in The Treatment of Psychological Trauma. For 25 years she has taught in Boston graduate schools of social work. While at Boston College School of Social Work she coordinated and taught in a National Institute of Mental Health funded program for Hard of Hearing and Deaf Masters in Social Work Students. She has presented to professionals throughout New England on the impact of trauma on attachment relationships, neurobiological development and behavior, and on the challenges of treating children, adolescents and adults who have experienced chronic psychological trauma. Candy is a consultant to greater Boston agencies, including The Massachusetts Department of Children and Families, where she trains social workers in the treatment of trauma. She has a private psychotherapy practice in Newton, Massachusetts.*

My name is Candy Saunders. I have a severe, progressive, genetic, sensorineural hearing loss, diagnosed in the second grade.

In considering the worst things about having a hearing loss, I am intrigued that I have spent my career teaching about the ways in which a person's attachment relationships define who she is, how she develops, and how she adapts to and survives trauma if she experiences it. For me the very worst thing about having a hearing loss is the relational aloneness that I can often experience in the midst of potential relational connections.

It is hard to define the actual experiences of hearing only a portion of what is being said in your presence. There are the accumulated feelings of longing, shame, numbness, rage, disappointment, and sadness that can accompany these moments. And there is the exhaustion from the investment of energy in efforts to survive them. There is the anxiety in anticipation of these moments. There is the helpless, frustration in the midst of these moments. And there is the vast range of feelings and reflections that gnaw at you long after these moments have come and gone. If I am with other people, I am in one of these three states, always.

Separate from this kind of aloneness, there is another kind. As a hard of hearing little girl, as a very social adolescent, and as an committed, adult Mom, partner, friend, and professional, determined to thrive in a world of hearing people, there has always been the aloneness of having to figure out how to deal with all of these experiences by myself.

"But you do SO well, Candy," "You are SO amazing at adapting, Candy," "If you didn't tell us, we would scarcely know that you were hard of hearing." I have heard these things countless times from audiologists, friends, family, and colleagues. The art of "doing SO well" as a hard of hearing person is often the art of pretending. It is the art of being able to appear to hear while hiding the psychologically and somatically consuming aloneness of chronically trying to

figure out what it is you are hearing, while rarely knowing for sure. The extent to which a hard of hearing person is “successful” is often contingent on the extent to which she hides her feelings, not only from others but also from herself. The only persons that I have sought to understand the true meaning for me of having a progressive hearing loss over the years are my audiologists.

I am fortunate for the adaptations I have discovered. I also know that my having had to discover them on my own has been costly on many levels that are hidden from even the closest relationships in my life.

Being asked to identify a single event or crisis of all the challenges that hearing loss has presented to me is very difficult. There are so many. An event that continues to carry pain for me happened around 25 years ago at the height of my career as a child and family therapist. I had had a lifelong passion for working with children and a reputation for doing it well. I taught courses in child development and child and family therapy in graduate schools and in organizations throughout New England. Because of the progression of my hearing loss, I decided to stop accepting referrals of young children and of families with young children in my active private practice. It was a painful but unquestionable ethical decision. I could ask my graduate students and young colleagues in classes that I taught, “What?,” “What? Sorry, say it one more time?” for a fourth or even a fifth time and use my usual strategies of explanation and humor to stay connected to them. I knew that it was not OK to try and do the same with my young clients.

I am lucky to have known considerable success as a teacher and child therapist. The intrusion of my progressive hearing loss on both of these areas in my career has been hard. The loss of working with kids is one that I have adapted to, but I would not place it in a category of having been resolved. As I acknowledge this, I experience one of those moments of rage and sadness in remembering another event that happened just four years ago. A beloved friend who

is also hard of hearing and who had attended her first Hearing Loss Association of America (HLAA) conference showed me a product that she had learned about there and then purchased. It was a personal fm system. The transformation that has occurred in my professional and personal life as a result of going to my audiologist and asking her to order this product for me is monumental in ways that I could talk about for hours. What I am less inclined to talk about is what it would have meant to me, to my family life, especially with my children, and certainly to my teaching and child therapy career had the only person with whom I shared my frustrations and from whom I sought solutions for them, introduced me to this product years earlier.

So what do I want from an audiologist? I want to work with a hearing health care professional that carries skills beyond hearing aid dispensing. I want that person to be knowledgeable about the most useful strategies in hearing rehabilitation such as auditory training and listening skills improvement. I want to see HLAA journals in the waiting room and to hear from my audiologist about the latest articles and research addressed in these and other journals that are relevant to my hearing needs. Currently HLAA is not listed in the “resources for patients” on the Academy of Doctors of Audiology (ADA) web site.

Something that I teach about in my own graduate classes is the documented resilience that persons who have known trauma can experience when, in the midst of their trauma or following it, they know the relational containment of those who can empathize with the trauma that has been theirs. I want an audiologist who understands this and who will invest in putting me in touch with others who share my experiences.

After testing my hearing a month ago, an audiologist in one of the world’s most renowned hospitals told me that I was now eligible for a cochlear implant in my left ear. She was in a hurry and let me know that someone would give me a list of implant surgeons in the waiting

area, where I could now take a seat. A few minutes later a nice gentleman in a white coat handed me the list and wished me well.

I am afraid of getting an implant. I am not ready to give up my career should anything go wrong. There is much that I want to learn about what this surgery will and could mean for me. What gave me the strength to rise from the waiting room chair and reduce the familiar numbness that had begun to rise inside me was my certainty that I would be able to connect with my friend, with my brother, and with implanted persons I met at my first HLAA conference last June who gave me phone numbers and cards and said, "Call me."

I was grateful as I walked down that hospital hallway that I did not feel alone.

#### Conclusion: Peggy Ellertsen

One day last June, as I was considering the possibilities for presenting at this symposium, I had lunch with my friend, Toni Iolacolucci, an active member of the Manhattan chapter of HLAA. She is a remarkable person who inspires me and makes me appreciate the power of the human spirit. Toni has lost all of her hearing, yet still, she remains engaged in living, giving to the people around her in ways that are unparalleled. I wanted to know what her ideas were about the merits of patient stories as resources for audiologists in caring for their patients' needs. She later sent me an email, and this is what she wrote:

"I'm just starting to realize that the 'psychology' of hearing loss..... overrides everything else..... You wouldn't be expecting audiologists to 'counsel', but I think it's the nuance of hearing loss (which will come out in the stories) that helps to target what people really need. If you don't go there in the client session, then how would you really know how what I need differs from what you need...and what options I would be willing to accept versus what you would accept?... My relationship with my audiologist is collaborative rather than hierarchical (as often

exists between doctor and patient/client.) There is clear recognition and respect for the fact that my communication needs are unique...My audiologist has worked and interacted with people with hearing loss in many different capacities beyond the office setting, and this adds great value to his understanding of the impact of this condition...and an ability to empathize with my experience.”

## References

- Compton-Conley, Cynthia. (2008). *Assistive technology for receptive communication*. Annapolis: Single-handed Productions, LLC.
- Harvey, M. (2010). What your patients may not tell you: combating deep metaphors and the rationale for audiological-psychological collaboration. *Hearing Review*. Retrieved February 2, 2012, from [http://www.hearingreview.com/issues/articles/2010-03\\_01.asp](http://www.hearingreview.com/issues/articles/2010-03_01.asp)
- Hickson, L. Defining A Paradigm Shift. *Seminars in Hearing*, Vol 33 (No. 1), February, 2012, pp. 3–8.
- Kochkin, S., Beck, D. L., Christensen, L. A., Compton-Conley, C. Fligor, B. J., Kricos, P. B., et al. MarkeTrak VIII: the impact of the hearing healthcare professional on hearing aid user success. *The Hearing Review*, Vol 17 (No.4), April 2010, pp. 12-34.
- Laplante-Levesque, A., Hickson, L., & Worrall, L. (2010). Promoting the participation of adults with acquired hearing impairment in their rehabilitation. *Journal of the Academy of Rehabilitative Audiology*, 43, 11-26.
- von Hapsburg, D., & Tjornhoj-Thomsen, T. The Encounter Model and Audiological Clinical Encounters. *Seminars in Hearing*, Vol 33 (No. 1), February, 2012, pp. 24-34.