

# **A View from the Patient's Side: How and Why I Became My Own Aural Rehabilitation Specialist**

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*Maps for Communication with Acquired Hearing Loss*

The purpose of this paper is to provide an autobiographical account of the experience of communication breakdown as a window into the impact of participation restrictions imposed by hearing loss. The author's active involvement with stress management and communication strategies acquired through a series of professional, para-professional, and self-help group experiences is described. The absence of non-technical therapies for hearing loss treatment in the practice of audiology, and solutions for implementing aural rehabilitation are explored. The benefits of aural rehabilitation are discussed in terms of patients who are actively engaged as well as patients who resist treatment, and in terms of patient satisfaction.

## **Prologue: Blind Alleys**

*Imagine that you are seated at a dinner table with eight dear ones. They have begun the animated, rapid-fire exchange of ideas that is the hallmark of this micro-community of smart and funny close friends, back and forth holding one conversation – persons A to E to C to A to F to H to A to G, etc., in no particular*

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*order. There is no way to anticipate who will jump in next. As the conversation becomes one discussion among the members of the whole group, you soon enough realize that the parties' language has shifted to a foreign tongue. You become hyper-vigilant and struggle to understand the meaning of their discourse, but for long periods of time – 10, 20, 30 minutes at a stretch – you perceive the talking as speech-like noise almost completely vacant of idea, detail, sense. You make a series of best guesses as to what the gist is, which you are sometimes able to determine accurately. No one stops the conversation to check in with you or to slow it down or to re-direct it to the vicinity of your place at the table, and you don't try to stop the conversation to adapt it to your needs either.*

*Even though you feel excluded – even though you are excluded – you experience exclusion in the moment that it is happening, not so much as a function of insensitivity on the part of your friends, but rather as a turning point in the progression of your disability. You understand that the spirited tempo of the conversation creates the bond among the human beings seated at the table. It grounds them, as it has grounded you during your many years of blessed good-enough hearing. It is what provides solid footing at the most essential level of human connection.*

*You ask for clarification a few times, but because you cannot make out nearly anything that's being talked about, you don't ask for help each time you are lost, because that would require you to ask over and over and over and over again. You have an awareness of the potential to layer the problem of disconnection from meaningful conversation with the additional problem of becoming an annoyance or even being thought of as unintelligent. You are quite sure that the demands of effective accommodation for you would be unnatural to the speakers, hard work that could easily become an irritation, a case of their having been asked to do too much.*

*Earlier in the evening for about an hour in the living room circle, and now again for another hour or so at the dinner table, you are set loose from the group, intermittently fighting off the menacing feeling that you are as alone as you can be: you are there, but you are not there. You are there, and yet you are somewhere else, because your mind is not working with the ideas of the conversation. Rather, it is working with the reality of the disconnection from conversation and, therefore, from the people whose conversation it is.*

*As long as you struggle to find your place in the discussion – any island on which you and a given speaker might share the same message for as long a moment as possible – your consciousness searches through the various paths of the linguistic maze that has, somewhere (you are certain), a small but real number of negotiable channels. You are searching, searching, for these, and as you search, you serially run into a generous sampling of blind alleys. It will only be later, after you've gone home, that the emotional impact of the evening fully holds sway over your resilience, and then you will know that you have once again hit a wall.*

*~ Personal Journal, 2/2010*

### **The Crisis: Maps Missing from My Navigational System**

The entry that I titled *Blind Alleys* in my personal journal was written late on a Sunday morning in February of 2010, my immediate response to an evening with friends that had prompted a crisis. The terrain of communication at group dinners with my eight close comrades had become so emotionally difficult to navigate, I began to seriously consider the possibility of limiting my participation in the frequent dinners that were the cornerstone of our connection. These are friends whose collective chemistry is extraordinarily wonderful when we all come together to break bread and banter, but the various characteristics and speaking habits that were part and parcel of our gatherings – lightning fast speech, raspy voice quality, a bushy mustache – had become barriers to the very raucous, topic-changing conversations that I had loved for many years. Despite my success with self-taught strategies for compensating in a variety of communication environments, the progression of my hearing loss ultimately rendered my repertoire of skills inadequate for the routine gatherings that encompassed multiple, talkative speakers seated around an intimate dinner table. As a result, persistent communication breakdowns began to accumulate, and they became costly to me in my relationship with people I love and with their impact on my emotional and physical health. The crisis that I wrote about in my journal landed me in bed with a splitting headache and the need for a few days rest.

One of the most important lessons that I have learned from my struggle with communication in the context of this group setting has been that maladaptive strategies come at a price. In my case, I had become a very good actor. I smiled passively and nodded and laughed at the right times, rather than teaching my

friends how to speak to me in a way that would help me to understand. I bluffed because *I didn't know how* to effectively communicate to them the depth of my need or the specific behaviors that I needed them to change. *I especially didn't know how to help them to remember* that I needed help. As a result, I waged a process of almost total reliance on my hearing aids. With the inevitable failure of that approach, I successfully fooled my friends into thinking I was fine as I put my energies into passing as a person with good enough hearing. Perhaps if my maladaptive strategy of choice had been a little less passive, they would have known right away that I was in trouble.

### **Strokes of Serendipity and the Beginnings of Cartography**

When a person with acquired, progressive hearing loss reaches the tipping point at which appropriately fitted hearing aids are no longer enough to facilitate successful participation in important areas of living, other, non-technological solutions become essential. Such solutions include communication strategies and stress management practices – i.e., rehabilitation tools that, together, can be characterized as “communication maps” because they provide guidelines to the individual as he or she begins to actively explore, negotiate and manage the often overwhelming functional and psychological challenges of disabled hearing. Using communication maps, the person with hearing loss learns to incorporate skills and perspectives for new ways of structuring communication, and new sets of behaviors that optimize the ability to live with a sense of authentic well being. The process of facilitating the mastery and use of communication maps by the listener with hearing loss is the essence of aural rehabilitation.

My own map-building began as a result of determination and sheer luck. On the advice of an acquaintance, I started to attend the annual convention of Hearing Loss Association of America (HLAA) in 2003 – an event that showcases a rich and varied array of aural rehabilitation resources. At that first convention, I learned of an innovative program that was being developed by rehabilitation audiologists Scott Bally, Mark Ross, and Matthew Bakke at the Rehabilitation and Engineering Research Center for Hearing Enhancement (RERC-HE) at Gallaudet University. Given the dearth of aural rehabilitation resources available to patients seeking help from audiology centers and practices, the RERC-HE rehabilitative faculty envisioned a professional certificate program to prepare people with hearing loss to mentor others with hearing loss. The Peer Mentoring Program

for Hearing Loss was subsequently launched in 2005. As a person trained in the field of communication disorders, my interest was piqued both intellectually and personally. In 2009, I applied for admission and was accepted into the program, which I quickly discovered is, in fact, a sophisticated and rigorous training in the principles and practices of aural rehabilitation.

A profoundly important byproduct of my studies at Gallaudet University became the transformative impact of working with colleagues who experienced the same challenges that I was facing, under the guidance of a group of audiologists whose holistic treatment model was based on the World Health Organization's *International Classification of Functioning, Disability and Health* (2001). My experience as a student of aural rehabilitation principles and practices at Gallaudet University helped me forge a new direction in my identity as a person living with a communication disorder. As I learned how to support others with hearing loss in their ability to work with their audiologists, I became more grounded in my own communication and self-advocacy skills, and began to expand and develop better strategies for coping. Since my completion of the Peer Mentoring Program in June, 2011, I have continued to immerse myself in professional resources made available by organizations that actively foster integrating holistic best-practices in hearing healthcare. These have included ASHA's Special Interest Group 7 for Aural Rehabilitation and Its Implementation, the Academy of Rehabilitative Audiology, the Ida Institute and HLAA.

### **The Maps in My Toolbox**

My experiences with the various stumbling blocks that I have confronted as a person with hearing loss have taught me the importance of building different sets of strategies and practices for a wide range of communication obstacles. A varied collection of maps helps the person who is hard-of-hearing put into cause-and-effect order the large number of destabilizing factors that can present themselves during challenging communication events. One set of maps that has become essential to me enables me to manage stress. Another set of maps help me more effectively control external variables that can either optimize communication events or contribute to communication breakdowns.

### **Maps as Stress Management Practices: Mindful Awareness and Self-Assessment**

The hearing loss crisis about which I wrote in my personal journal was largely precipitated by physical and emotional stress that had accumulated over a series of evenings characterized by communication failure. As communication breakdowns mounted, I became routinely overwhelmed by the demands of trying to decipher conversation and by debilitating, automatic cognitive and emotional responses to my inability to do so. Like many people whose solution to hearing loss is limited to a focus on the audiogram and hearing aids, I had unwittingly slipped into the unfortunate pattern of heavily relying on amplification to passively solve my communication problems. This method for coping resulted in what we know to be the likely, dispiriting outcome when the severely hard-of-hearing patient practices sole reliance on even the very finest hearing aid technology.

Chronic restriction from participation, especially with valuable communication partners, often yields devaluing beliefs about characteristics of the self, including incompetence, worthlessness, and lowered social status. These thoughts easily mingle with emotions such as sadness, despair, panic and weariness about communication situations and the inability to control them (Trychin, 2002a). When the person with hearing loss is inundated with such negative thoughts and feelings, the very well-being that is required for the strategic work of listening is reduced (Harvey, 1998; Hogan, 2001).

Communication maps for stress management are especially helpful for the person with hearing loss who experiences chronic stress responses. Two such tools are mindful awareness and self-assessment. Mindful awareness, typically achieved through the practices of meditation and yoga, involves using the mind to pay attention to the way the mind is working as a person actively observes his or her physical, psychological and emotional experiences (Siegel, 2007). Mindful awareness reduces stress, increases well-being, and facilitates a second stress management tool, self-assessment. This tool involves evaluating reactive thoughts that come up in consciousness when a person with hearing loss experiences difficult listening conditions and enables the person to interrupt automatic internal scripts (e.g., *It's not working; I should not have come; It's no use*) and to posit realistic alternatives that offer material relevant to problem-solving (e.g., *They're great friends, but three hours is too long a time to expect them to speak so slowly; next time I'll ask for changes just at the dinner table.*) (Harvey, 1998).

For the person with hearing loss, stress management practices can lead to the important outcome of an *awareness of the possibility* of control as a primary eliminator of stress, even more so than the exercise of control *per se* (Erdman, 2011). Mindful awareness and self-assessment have helped me to reduce stress by improving my responses to hearing failure with an increase in strategic thinking. As a result, I have become more confident in my ability to accurately evaluate communication events – even in the midst of communication breakdown. With the practice of stress management behaviors, I can more readily recognize factors in challenging listening environments that can be changed and those that most likely cannot. As a result, I am better able to direct my thoughts away from unalterable factors that have tended to distract me from more skillful listening and focused attention.

My routine use of maps for stress management has been buttressed by lifestyle changes that optimize my physical, cognitive, and emotional well-being. Increased attention to diet and aerobic exercise now supplement my daily practice

**Table 1**

Self-Assessment Map: Emergent Self-Assessment After Group Gathering at Friends' House (February, 2010)

Affective	Cognitive	Behavioral
Surfacing of vague feelings of dread	<i>If I listen as hard as I can, I'll catch some of the punch lines.</i>	Watch speakers carefully to lip read
Increasing sense of failure as communication breakdowns accumulate over the course of the evening		Make sure batteries are fresh. Adjust volume of hearing aids, try to sit in a position where wall is directly behind me. Make sure lighting is optimal.
	<i>Is there anything I'm overlooking?</i>	Watch speakers carefully to notice their affect as a model to use, "as if" I'm engaged in the conversation.
Sadness, despair	<i>There's nothing else I can do.</i>	Bluff to stay in the game.
	Consider limiting participation.	

**Table 2**

Self-Assessment Map: During and Immediately Following Group Gathering at Friends' House (January 2011)

Affective	Cognitive	Behavioral
	<p><i>If they are aware of how much difficulty I'm having, they'll speak with greater clarity.</i></p>	<p>Disclose the progression of my hearing loss, how untenable group dinners have become.</p> <p>Meet with members of the group, share portions of my journal, brainstorm together.</p>
<p>Somewhat increased sense of control, enjoyment, somewhat increased relaxation, ability to laugh at the problem</p>	<p><i>"They're having difficulty changing their pace."</i></p>	<p>Tell them I really need them to slow down for me.</p>
<p>"in process" emotional orientation begins to emerge</p>	<p><i>No...It's that they're having difficulty remembering to slow down.</i></p> <p><i>It's especially challenging for everyone to change.</i></p> <p>Maps begin to emerge for visual pneumonics.</p> <p>Consider individual speaker expectations.</p> <p>Think about strategies for re-training that incorporate levity.</p>	<p>At home, create a new scheme to teach specifics of speaker behavior to be modified.</p> <p>Make personalized visual "memory aids."</p> <p>Make them catchy, funny.</p>

of yoga and meditation. Such routines fortify my physical energy, emotional endurance, and ability to focus and sustain attention. In doing so, they condition my readiness for self-assessment when communication begins to fail (see Tables 1 and 2).

**Maps as Communication Strategies**

Maps for stress reduction that enable persons with hearing loss to modify internal cognitive and affective responses to communication breakdown are complemented by several models of communication strategies that provide tools for changing communication events themselves (Kaplan, Bally & Garretson, 1999). The Communication Model, for example, supplies the person who is hard-of-hearing with a map that enables him/her to identify and experiment with aspects of a communication situation as a function of one of three contributing



sets of variables: speaker, acoustic environmental, and listener features (Bally, 1996). The process of assessing and maneuvering such communication variables through trial and error has been aptly referred to as “loading the dice in our favor.” (Trychin, 2003a, p. 1; Wayner & Abrahamson, 2001, p. 17)

During the time before I began to study more structured models of communication strategies, I had begun to shape my responses to challenging listening situations from a commonsense approach. For example, in the large parish hall of my church during coffee hour after the Sunday service, I developed the habit of holding conversations while positioned near the perimeter of the hall in order to reduce the impact of background noise and reverberation. Incorporating more systematic communication strategies in my repertoire of skills, however, enabled me to expand my informal efforts.

With my study of communication strategies, I became knowledgeable about improving my odds in any encounter by clearly and specifically requesting changes in speaker style. I also began to understand the factors that influence a speaker’s speech habits that needed to be modified. This shift to a more strategic, planned approach to changing speaker variables helped me to develop an orientation toward re-training speakers’ habits based on a greater appreciation for the fact that the changes that I was asking speakers to make were not easy ones for them to sustain.

In particular, Trychin’s work offered me a framework of skills that helped me more deftly request and achieve changes in speaker variables by maintaining a largely empathic view of the speaker’s task (Trychin, 2003a). I became more conscious of how important it was for me to adapt to speaker needs and expectations as I asked speakers to adapt to my needs. Moreover, the process of considering the perspectives of individual speakers as I asked them to alter life-long communication habits became more automatic for me with practice. I began to routinely build hunches about transient speaker factors that tended to shift from one gathering to the next. For example, on any given occasion, the day-to-day challenges of living and an individual speaker’s level of fatigue might distract my partners from modifying their rate and intensity of speaking. Assuming an empathic approach to understanding the cause and effect of breakdown in speaker variables helped me depersonalize communication failures, evaluate them more accurately, and adjust my requests.

Finally, as I offered my communication partners reminders of what I needed them to do, I began to chunk the behavior changes I was requesting into shorter time frames (*just at the table during dinner*) and simpler bullet points (*a little volume, slowly, one-at-a-time*). I also introduced to our gatherings a consistent

supply of high interest visual cues and became more conscious of indications that the effectiveness of one visual cue had weakened and that it was time to change to another.

The impact on communication events made possible by such strategic approaches has been subtle - perhaps imperceptible to other members of my group of friends - but it is hard for me to overstate how powerful these strategies have been in achieving just enough change to keep me in the conversation. Understated

**Table 3**  
Communication Strategies Maps

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**1. Essential Components of the Communication Encounter (Bally, 1996)**

<u>Environmental Factors</u>	<u>Speaker Factors</u>	<u>Listener Factors</u>
-lighting -seating arrangement -background noise -distance from speaker -acoustic properties of space	-rate -volume -physical characteristics (e.g., mustache, etc.) -obstruction of mouth with gesture -speaker group size -mood, fatigue, attentional style	-use of amplification (hearing aids, ALD's) -effective self-assertion -ability to self-monitor, maintain energy -ability to self-regulate mood, internal reaction to stress -ability to actively prepare, manage time plan anticipatory schemes

**2. Listener Attitude and Behavioral Style (Kaplan, Bally & Garretson, 1995)**

<u>Passive</u>	<u>Assertive</u>	<u>Aggressive</u>
-may bluff -may avoid use of amplification -may withdraw excessively -may become overly reliant on others	-communicates clearly -positive -plans actively -listens strategically -asks for clarification -verifies perceived message with the speaker	-may function with poor emotional regulation -may over-emphasize role of external factors in communication breakdown

**3. Key Features, Assertive Disclosure of Hearing Loss and Requests for Modification- (Trychin, 2002a)**

<u>Specificity</u>	<u>Explanation</u>	<u>Courtesy</u>
request <i>specific</i> behaviors of the speakers(s): "Talk very slowly like this..."	inform interested speaker reasons why a given modification will help: "Because this room produces so much echo. A slower rate of speaking will minimize the distortion from the echo."	ask for modifications with consideration and appreciation: "I really want know what you're saying, and slower speech will help a lot. Thanks!"

**4. Language Pragmatics: Sample Checklist of Questions for Re-training the Speakers**

- What is the estimated amount of time each person can comfortably pay attention to and sustain modifications in his or her own speaker features?
- On any given evening, are individuals in the group tired? distracted?
- Is there a high interest theme that could be used in visual cuing that would help this group to remember speech modifications? Would a different theme for each person help memory, sustain motivation?
- Who needs the "Cliff Notes" version of my predicament? Who wants to know more?

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modifications in speaker habits have provided me with increased access to the semantic context during group conversation, supporting my auditory comprehension and sustaining me within communication events. Thus, the possible modifications that I have learned from my introduction to communication strategies have helped me to hold onto an authentically meaningful place in one of the most important conversation circles of my life (see Table 3).

### **Hard-to-Come-By Aural Rehabilitation**

Not every person with hearing loss is handicapped by an inability to hear normally, nor are all persons with hearing loss destined to confront a crisis in confidence or compromised physical and emotional wellbeing (Hogan, 2001). We do know, however, that hearing disability puts individuals at risk for stress related illness and other potentially handicapping effects such as reduced productivity at work (Kramer, 2011). In my case, low-level fear and worry about my hearing was present during much of my adulthood, and these emotions escalated when I first realized that the progression of my hearing loss had begun to handicap me in important areas of my life. Ultimately, the services of a skilled and patient audiologist were enhanced by a set of fortuitous opportunities for me to study aural rehabilitation practices and apply them to my own functioning. This combination of resources enabled me to move on from a difficult crisis to significantly improved communicative functioning.

I consider myself to be incredibly fortunate. Although I am grateful for my positive outcome, it is unsettling to me that the field of aural rehabilitation remains largely non-existent to the average audiology patient. This is the case despite growing evidence that a wide range of aural rehabilitation treatment approaches are associated with a positive impact on quality of life, decreased participation restrictions and activity limitations (Hickson, Worrall & Scarinci, 2007), and other important changes such as improved uptake rates in the use of amplification (Northern & Beyer, 1999). Especially disturbing, recent studies investigating hearing loss as a putative risk factor for dementia, while not conclusive, provide evidence that hearing loss is independently associated with dementia and that the risk of dementia increases with hearing loss severity (Lin et al, 2011).<sup>1</sup> Even

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<sup>1</sup> Researcher Frank R. Lin, M.D., Ph.D., of Johns Hopkins School of Medicine suggests three possible causal relationships of hearing loss to dementia: (1) The impact of difficult auditory perception on cognitive function as the brain allocates resources to auditory processing, to the detriment of functions such as working memory; (2) the impact of social isolation that is a common outcome of hearing loss, especially in older populations; (3) lower levels of environmental enrichment and their impact on the brain (2011).

in the face of such positive links between hearing loss and devastating cognitive consequences, aural rehabilitation remains very difficult to obtain.

In the 2010 Marke Trak VIII Survey, Kochkin et al. (2010) examined the components of treatment protocols used by audiologists and the relationship of those components with successful hearing aid outcomes. The impact of aural rehabilitation and referral to self-help groups could not be established because so few of the respondents included in the study reported having received either of these measures. Only 18% of new hearing aid users and 9% of experienced hearing aid users reported receiving aural rehabilitation services, and the average amount of time spent by the two groups was only 30 minutes. Only 2% of new hearing aid users or experienced users reported receiving a referral to HLAA by their hearing healthcare specialists (Kochkin et al., 2010). These findings raise important – even urgent - questions about how we can implement a wider array of patient-centered options in the practice of audiology, with a broader vision for what needs to be made available to persons who are hard-of-hearing when they lose significant islands of functioning. What are the apparent obstacles getting in the way of our building aural rehabilitation routines into the typical treatment protocol for patients who would benefit?

Four likely factors impeding the implementation of strong aural rehabilitation practices are posited by Dr. Harvey Abrams, Director of Audiology Research at Starkey Laboratories, in a *Topics in Audiology* article posted on the American Speech-Hearing-Language Association website (Abrams, 2012). These include concerns about the effectiveness of aural rehabilitation as reported in the research, weak reimbursement systems for third-party compensation, the perception that patients would be unlikely to pay for aural rehabilitation services, and lack of time. In addition to these obstacles, I believe that patients who are hard-of-hearing tend to self-stigmatize and resist treatment. As a consequence, building robust aural rehabilitation programs into the practice of audiology might be perceived as a futile exercise by some professionals. It also might be the case that pressures experienced by private practitioners to attract first-time hearing aid users and to sustain a consistent client base from a referral group wary of treatment may lead to the belief that such referrals might be lost if flooded with the introduction of yet another intervention measure. For these reasons, there is resistance to change, but there are strong counter-arguments and reasonably achievable solutions.

Abrams, for example, addressed questions about aural rehabilitation effectiveness as reported in the research with a discussion of the difficulties related to small sample size in outcome studies. He noted that such weaknesses in research design are mitigated by the application of meta-analysis in the statistical treatment of data (Abrams, 2012). That is, when investigators have combined smaller studies in a single analysis, the findings frequently have yielded support for the hypothesis that aural rehabilitation programs are effective, both for individual and group treatment models.

Moreover, in his 2000 paper, *When a Hearing Aid Is Not Enough*, Dr. Mark Ross refuted the notion that the effectiveness of aural rehabilitation remains unproven. He reviewed five separate studies on patient outcomes and found that reduced handicap and improved patient satisfaction were consistent findings. Dr. Ross concluded, “The overall research on this topic seems fairly unambiguous... there is convincing evidence that those people who receive enriched counseling services show a greater reduction in the hearing handicap than those who received less such services” (p. 2).

The challenges of third party reimbursement policies that limit the availability of aural rehabilitation therapies to patients who are hard-of-hearing can be avoided with alternative aural rehabilitation solutions that are virtually cost-free to the audiology practice and are of low cost to the patient. One example is the partnership between audiology practices and university aural rehabilitation training programs, providing internship placements for graduate level interns and enabling the availability of aural rehabilitation services to patients. When aural rehabilitation is delivered through the services of audiology trainees, both students and patients are provided with important learning experiences (Thibodeau & Cokely, 2003). Graduates from Gallaudet University’s Peer Mentoring for Hearing Loss Program provide a second alternative solution. Peer Mentors who have completed that program now number approximately 25, and 17 candidates currently are in training. As Peer Mentoring for Hearing Loss grows as a para-professional resource, these mentors can be used as sources of aural rehabilitation in both clinic and private practice settings, especially with the increasing use of telehealth healthcare delivery applications (Houston, 2011). Although it is important to be mindful of the differences between aural rehabilitation programs provided by self-help groups and those provided by hearing healthcare professionals, referral to HLAA is a way to make aural rehabilitation tools immediately available to

patients. Such referrals also should facilitate an introduction to a local chapter member who can serve as an emissary and contact.

Many of these potential additions to aural rehabilitation treatment protocols can provide persons who are hard-of-hearing with opportunities to develop positive alliances with others invested in solving the problems of hearing loss. Such partnerships commonly address the psychological and emotional needs that have been identified in qualitative studies of patient narratives, *including the wish for transformation, the importance of sharing one's story, and the desire for the development of trust in the course of treatment* (Harvey, 2010; LaPlante-Levesque, Hickson & Worrall, 2010; Zaltman & Zaltman, 2008). The effectiveness of peer support groups in helping participants address such needs is often mirrored in testimonials from hard-of-hearing persons who have become involved in HLAA. The following are examples:

On a personal level, I do not exaggerate when I say that HLAA gave me back my life after a sudden and severe hearing loss 25 years ago....I was... thinking that never again would I feel the joy and richness of my pre-hearing loss life. Thanks to HLAA, I learned that although there was no magic pill, there were many strategies I could use to help myself. I received not only information, but also support and encouragement.

Ann Pope (HLAA website, 2012)

...Life-changing is an expression that's used frequently when people talk about their engagement with HLAA.

Toni (HLAA, 2012)

...changed my life. Through active involvement, I re-gained confidence and learned how to cope more positively with my progressive hearing loss. I have had the opportunity to watch others grow as I did.

Julie (HLAA, 2012).

Such testimonials suggest the power of active collaboration with others as a means of demystifying living with hearing loss. Human connection as an important component of successful treatment becomes even more compelling when we consider the functioning of patients who resist treatment.

The literature examining the impact of stigma on personal identity with the onset of hearing loss related communication disorders has created a significant paradigm shift in the way that we understand the strong tendency to avoid treatment by people who are hard-of-hearing. For example, in their October, 2011 ASHA Online Conference presentation, rehabilitation counselor Anthony Hogan and social psychologist Kate Reynolds discussed the uniquely perplexing dilemma of loss of identity and place in the established social context when an individual becomes unable to communicate normally. The person who loses hearing is confronted with the requirement that verbal exchanges previously taken for granted must be strategically managed, and commonly understood and followed rules of communication must be renegotiated, although the partners may not validate such modifications (Hogan & Reynolds, 2011). Framed this way, persons who are hard-of-hearing who deny their disability or evade treatment can be recognized not so much as difficult patients, but as individuals confronting a fundamental threat to their functioning. The threat carries the potential to compromise not only communicative competence, but also self-perception and identity. Consequently, self-stigma and denial very likely play an important role in the fact that a staggering 75% of people with hearing loss currently function without treatment (Kochkin et. al., 2010).

The psychosocial problems associated with hearing loss can rarely be managed alone, regardless of amplification use. With no standard or accepted current model for hearing loss treatment to facilitate the processes of acceptance and adaptation, it should not surprise us that avoidant response styles are so prevalent. Rehabilitation must address the fact that acclimation to hearing loss can take time and demand significant courage from the ambivalent patient. Progress likely is individualized as each person with hearing loss brings unique characteristics to the course of adjustment (Southall, Gagne, & Jennings, 2009). Non-technical aspects of rehabilitation that cultivate a trusting, supportive alliance might well improve success rates and engage a wider range of patients.

### **The Patient's Voice**

Disability literature suggests that the patient narrative should be a centerpiece of the healthcare process. Most notably, the World Health Organization's *International Classification of Functioning, Disability and Health* (WHO ICF, 2001) established the client's statement of functional difficulties and goals as

a critical element in the healthcare professional's work on behalf of the patient (Gagne, 2011). Importantly, in 2003, the WHO ICF was adopted by the American Speech-Language-Hearing Association as a key scaffold in its Scope of Practice in Audiology. Although this important framework was designed to guide the creation of best practices, its adoption as a standard component of hearing healthcare has been limited, especially with regard to assisting patients with their thoughts and feelings about important challenges and goals as they surface over time.

Including a patient's emergent voice is fundamental to the treatment process and a crucial component of successful audiology practices. I believe that of all of the steps that need to be taken towards implementing aural rehabilitation, allocating time for a collaborative review is one of the most important. Sessions should have time set aside for talking and listening, with consistent exploration through a needs assessment and decision guide with a member of the audiology staff or support team. I believe that such a practice achieves a number of essential therapeutic objectives.

First, unhurried, periodic collaborative reviews by the client and a member of the audiology staff provide a vehicle for facilitating the long process of acceptance and adaptation of active management. As a cornerstone of hearing healthcare, this type of patient support both facilitates empowerment and addresses the underlying dynamics of denial and aversion to treatment so frequently associated with patients who have hearing loss.

Second, the opportunity to talk and listen provides audiologists with time to encourage patients and provide feedback.

Third, regular collaborative patient reviews foster a shared decision-making relationship in which the client-clinician dyad can together craft maps for critical areas that the client wants to begin to more skillfully navigate.

Fourth, a regular needs assessment with one of the excellent instruments available for evaluating functional categories of a patient's life provides the structure to highlight the important short and long term goals in the patient journey and enables the client and audiologist to focus on and organize both technological and non-technological objectives as the client becomes ready to do so (Compton-Conley, 2008; Thibodeau, 2011).



Fifth, the active use of a decision tool informs and empowers patients to better create accurate expectations for treatment options and allows consideration of new choices with each session (Laplante-Levesque, Hickson, & Worrall, 2010).

Sixth, and perhaps most important, periodic appointments with collaborative review allow clients the opportunity to retrieve, in many cases very gradually, the critical parts of their stories that cannot be accessed during the time allocated to audiometric assessment, review of the audiogram, and hearing aid fittings (Harvey, 2010).

Finally, a routine collaborative review not only provides therapeutic benefit to the client; the professional also achieves objectives that promote growth and maintenance of a successful audiology practice. For example, information collected from patients with needs assessments and decision tools helps clinics to anticipate overall patient uptake rates by revealing characteristics of patients within the caseload that are robust predictors of patient follow-through (Laplante-Levesque, Hickson & Worrall, 2012). Collaborative reviews help clinics develop and plan aural rehabilitation programs that match the needs of patient constituencies within the practice. For instance, when a sufficient number of patients indicate readiness for exploring the use of assistive technologies, efficient, cost effective group programming can facilitate adoption and use of new devices by a number of patients (Thibodeau, 2007). Collaborative patient reviews also aid in aural rehabilitation planning by providing clinics with current patient narratives that can be used to determine the proportions of patients who are managing well with hearing aids alone, who are beginning to struggle, and who have begun to experience significant activity limitations and participation restrictions.

Lastly, collaborative patient reviews help audiologists build a high level of patient satisfaction by providing opportunities for patients to develop trust and tell their stories as they emerge and evolve over time. Incorporating such essential patient experiences into the practice model will very likely contribute to the vitality and success of the practice (Cooke, 2012).

### **Final Thoughts**

We live in a time that has been blessed with revolutionary changes in sensory technologies that provide patients like me with an essential link to spoken language. It is hard for me to imagine what would have happened to my life without my

audiologist's expertise and steadfast approach, as well as the remarkable digital hearing aids and FM device that she helped me select and which allow me to function. This also is a time in which evidenced based rehabilitative audiology research is yielding tools that have the potential to decrease and, in some instances, even eliminate certain activity limitations and participation restrictions for patients for whom hearing aids alone are no longer an adequate solution. We know that aural rehabilitation treatment models are the means by which bridges to human connection and well-being are built for this group of patients as well as for those who resist treatment. I hope that in sharing my story and in writing about the principles and practices that I continue to study, I am able further this important work.

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