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An Examination of Living with Hearing Loss in an Inaccessible World: When Hearing Aids are Not Enough

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Janine Verge, AuD, Aud(C)
Hugh J. Haley, PhD, C.Psych

In this edition of Issues in Accessibility, I interview Dr. Hugh J Haley, a psychologist who shares his personal experience living with hearing loss and the challenges and barriers he has encountered. As a psychologist, he reveals a special insight into the functional and emotional impact of living with hearing loss and the positive and negative experiences he has had in the field of audiology. He offers suggestions on improvement and sends a clear message to businesses and organizations in our community on the importance of providing an accessible environment.

Janine Verge: Can you tell me about your background living with hearing loss? When did you first start to notice challenges?

Dr. Hugh J Haley: Although I have had hearing challenges for as long as I can remember, it became much more pronounced when I began to have difficulty following the conversations of a significant number of people about 18 years ago (age 53). As a psychologist, listening to people was a major part of my professional life. With the assistance of hearing aids, I was initially able to function effectively in one-to-one conversations and in small groups, but as my hearing quickly diminished, I was totally ineffective in any group of over 3–4 people. Within about 5–8 years, I could no longer facilitate workshops and training sessions, so teaching was extremely difficult for me. Then after a couple more years, I could no longer follow what was being said in large social gatherings, such as movies, theatre, church, or lectures. Eventually, I had to reduce my professional, social, and recreational activities because of the challenges, particularly in group settings.

Within the last 8 years, I have become more dependent on assistive devices to transmit wirelessly from my telephone and television directly to my hearing aids. Combined with occasional closed captioning, this produced amazing assistance. I could then easily follow television, radio, or telephone dialogue with the help of these technologies. However, these were restricted to personal arrangements in my home or workplace and required a fair amount of technology. This limitation meant that I was still unable to participate in social or group settings, such as lectures, movies, or theatre, which had the effect of socially isolating me.

Janine Verge: What listening situations do you find challenging?

Dr. Hugh J Haley: As my hearing declined, I was unable to continue a number of very rewarding aspects of my professional life, and eventually reduced my activities to one-on-one services, such as individual, small family and couples therapy, and one-on-one interviews. Even then, there were incidents when I was unable to work with certain individuals because of their soft voice or accent. Continuing professional training was limited to literature reviews because I was unable to engage in workshops or teleconferencing. Initially, this was of diminishing concern as I moved into part-time retirement, was more interested in a different pace of life, and exploring new expanded life interests. However, just as I was anticipating retirement, long delayed post-retirement aspirations were also becoming closed to me. Although I retired to a university town to take advantage of lectures, courses, and intellectual dialogue, I could no longer follow them. It became increasingly difficult to follow the dialogue in movies or theatre and as I pursued my interests in travelling, I was unable to follow the information provided by tour guides. I now seldom attend groups, restaurants, or social activities because communication and noise levels are such a barrier. My interests were becoming restricted to television which led to social isolation, which has led to depression and reduced physical activity.

Janine Verge: What has the functional and emotional impact of living with hearing loss been like for you?

Dr. Hugh J Haley: Physically, the greatest challenge is dealing with situations in which there is competing noise or in which the sound quality is poor. Any background noise is physically uncomfortable and distracting, tending to drown out what I am attempting to hear. Even in a small group, I have difficulty following a conversation because it is difficult to converse with someone who is a distance away or is not directly facing me. In order to have a conversation with someone, I need to isolate them from the larger group of people, or into a small group of 3-4 max. Then I don't want my companion to leave, or to include anyone else, or I will be left out of the interaction. Even with a small face-to-face group, I can often misunderstand something, which can be funny, or, more often, embarrassing. This means that I often isolate or monopolize individuals; an unconscious tendency I must constantly guard against. It is often easier to avoid groups of people, or any social situation involving several people, as well as any loud environment where sound becomes an unpleasant endurance.

Emotionally, the social inactivity and isolation that results from a lack of social and recreational contact is most acute because it is pervasive. I am alone when I am with people, and I am alone when I avoid being with people. When in a social situation, I tend to isolate myself to avoid being in an awkward situation, which precludes meeting new people. Others misperceive this as wanting to be alone, when I would very much welcome social contact. This isolation takes a strong emotional toll, and, as a professional, I am aware of a constant battle with depression and a lack of motivation to keep engaged. It becomes a vicious cycle, which I must constantly struggle with.

Janine Verge: Thank you for describing your personal experience with the emotional and physical challenges you struggle with. I think it will be eye opening for readers to understand what people living with hearing loss must go through. You mentioned greater challenges when you are in an environment with background noise. What barriers have you encountered with background noise in your daily life?

Dr. Hugh J Haley: The barriers for me are sound: too much and not enough. It is difficult for me to understand speech without the increased volume from the hearing aids. The effect of this increase in loudness can be uncomfortable and distracting in any situation. The hearing aid in social situations also increases the loudness of background noise which increases the discomfort and comprehension challenges of the hearing aid. Loudness, which background noise increases, causes psychological stress and fatigue and makes comprehension difficult. The challenge is finding a hearing environment in which I can hear effectively and comfortably with hearing aids without the background noise distorting the sound to the point that it becomes incomprehensible and intolerable. Most social environments in our society work against this, often inserting sound where it is not necessary and disruptive for people who are hard of hearing. Examples are music in restaurants, background sound in television, film, and theatre, and poor acoustics in restaurants and recreational facilities, often with the intent of increasing social stimulation.

Most social, recreational, educational, and economic activities are carried out in environments which have background noise levels in which I cannot effectively process speech. This reduced capacity to take part in my community has not only drastically restricted my professional life, but also the inability to appreciate social and cultural events such as theatre, concerts, or lectures. I no longer teach or give seminars, I have drastically restricted my volunteer work, I seldom attend social events such as parties, and haven't attended a movie or theatre in years.

Janine Verge: What impact does an inaccessible environment have on your ability to participate in your community?

Dr. Hugh J Haley: When I anticipated retirement in good health, I envisaged participating in social and volunteer activities, for which there were limited opportunities while working and raising a family. Unfortunately, most of these opportunities were quickly restricted by hearing loss. I had also anticipated enjoying many solitary activities, such as reading, gardening, and correspondence, but these activities can become isolating without the benefit of the social component of sharing them with others in groups, artistic expression, and related media. As social beings, it can be difficult to maintain engagement in any activity if conversation and dialogue with others is lost. As a person's hearing loss increases, there is an increasing risk of isolation and lack of active involvement in many of life's activities.

Janine Verge: What advice do you have for audiologists to support people with hearing loss when hearing aids alone are not enough?

Dr. Hugh J Haley: Like most people, I hadn't given much thought of what to expect from an audiologist until I went for my first hearing test.

The public is exposed to pervasive advertising about the great benefits of hearing aids, promoting the belief that people with hearing loss do not have to be restricted in life activities if they wear hearing aids, and each hearing aid company strongly implies that their individual product is the best. Objective criteria of how one device would meet the individual requirements of specific clients appear to be limited. People rely on audiologists for their expertise on which hearing aid device is best since people can typically only try one or two different devices. A patient seeking the advice of an audiologist anticipates that they would provide the best options available. I realize that this is simplistic but it appears that part of the decision of a hearing aid prescription may be determined by the audiologist's preferences or relationship with a specific manufacturer. People living with hearing loss may have expectations that can not be met even with the best set of hearing aids and this false expectation might affect the ability to address all the rehabilitation options that may be available.

There are many other assistive listening devices, besides hearing aids, that people who are hard of hearing could benefit from. These, however, do not appear to fit easily within the hearing aid marketplace and they do not appear to be a priority of the health system. For me, the experience of direct wireless connection from my hearing aids to the television has been the most dramatic benefit to help with hearing. From what I understand, other assistive devices that could help such as telecoil devices, are not regularly discussed with patients or promoted by audiologists. If people with hearing loss were made more aware of these assistive devices there would likely be a stronger demand for them. Audiologists could help support people with hearing loss by focusing more on how to connect their hearing aids to other assistive listening technologies that could help them in their community.

I feel as though I could have benefited from more information as to why a particular device was being suggested, what the advantages or disadvantages were of different options, what additional devices or interventions might have been considered to address my specific listening needs, and how I could obtain more assistance with my hearing challenges beyond hearing aids. A person living with hearing loss should be made aware of the large number of hearing options available to them and be encouraged to advocate for them. Although this is done to varying degrees in different facilities, they should also be counseled that the social, psychological, and neurological challenges of hearing loss are not solved simply with the provision of a properly functioning hearing aid, but require personal self-management, support systems, and work to obtain them.

Janine Verge: What advice do you have for businesses and organizations to create a more accessible community?

Dr. Hugh J Haley: In spite of the fact that hearing loss is so common, there is a great deal of misinformation, and lack of understanding, as to what might be made available to engage this segment of the population in their community. A large number of people with hearing loss are not able to take full advantage of leisure activities and amusements, such as social group functions (cards, bingo, dances), entertainment (movies, theatre, concerts, sports), and participation in employment, voluntary and advocacy services.

Businesses and organizations need to understand that hearing aids alone are not enough. The onus of accessibility cannot be put solely on the person living with hearing loss. Businesses and organizations need to create accessible environments including getting rid of any unnecessary background noise, using microphones when having public presentations, using assistive listening technologies so people can directly connect to these systems with their hearing aids, having a process for feedback so they are aware there are barriers, and having proper signage so people know where they can access help. Having captioning available for videos and presentations is also important. It will allow a greater number of people who will be able to access services in their community, which in turn, will be good financially for business and organizations – a good incentive.

Janine Verge: As a psychologist with hearing loss, what advice do you have for Audiologists to help address the emotional and physical consequences of living with hearing loss when counseling?

Dr. Hugh J Haley: I’m not able to comment on research or literature on the psychological consequences of hearing loss, but there are a number of comments I could make from my personal experience, as a person who became hard of hearing in adulthood. As I tried to describe above, hearing loss is a major disruption of one’s established life pattern, especially in the employment, social, and recreational activities of today’s work and social environments. While hearing aids do provide substantial assistance, they do not restore hearing. Living with hearing loss can cause people to gradually lose access to many of the daily activities of living that they are accustomed to participating in. The resulting social isolation, diminishing engagement, and decreased participation in many common activities (lectures, theatre, group activities), can affect both physical and psychological wellbeing. Assistive devices such as hearing aids and their accessories focus on supporting participation in solitary activities, such as tv, radio, and limited one-on-one contact. However, this often has the effect of increasing the isolation. Lack of additional support and access for larger group activities is a profound burden of living with hearing loss.

It is also important to recognize that the experience of coping with hearing loss and its resulting limited access to previous activities is a very personal and uniquely challenging experience. Coping with the additional challenge of adjusting to hearing aids in different environments can increase the psychological impact of hearing loss. It is difficult for another individual to appreciate the personal challenge of assessing the relative benefit of a specific hearing device, while adapting to a substantial increase in sound input and learning how to maximize their hearing experience in varied social and physical environments. This is significant because of the varied impact of sound on the individual's physical and psychological functioning. As a stimulus, loudness can elicit feelings of stress, anxiety and anger which can further interfere with coping in different hearing environments. The hearing aid's increase in volume may not only make comprehension of sound messages difficult and tiresome, it may cause undesirable psychological challenges.

The health system needs to assess and address all the listening needs of people living with hearing loss. Information and management strategies, rather than a singular emphasis on hearing aids, would enable them to more effectively manage their hearing loss as well as increase access to environments in which they are struggling. An audiologist is in the best position to assist people living with hearing loss to work within these limitations and learn to become proactive in taking control of their specific challenges. They need to explore other devices or technologies (such as hearing loop systems), social support systems, and recreational activities that they could try. If audiologists encourage their patients to look beyond a specific hearing aid solution, the person living with hearing loss will be able to find out more about the specific barriers they have to deal with and are more likely to recognize the emotional consequences of living with hearing loss. It will provide a feeling of empowerment to take control of their own situation and expand the options available to them.