Scientists with Hearing Loss Changing Perspectives in STEMM

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Despite extensive recruitment, minorities remain underrepresented in science, technology, engineering, mathematics, and medicine (STEMM). However, decades of research suggest that diversity yields tangible benefits. Indeed, it is not surprising that teams consisting of individuals with diverse expertise are better at solving problems. However, there are drawbacks to socially diverse teams, such as increased discomfort, lack of trust, and poorer communication. Yet, these are offset by the increased creativity of these teams as they work harder to resolve these issues (Phillips, 2014). Although gender and race typically come to mind when thinking about diversity, people with disabilities also bring unique perspectives and challenges to academic research (think about Stephen Hawking as the most notable example). This is particularly true when they work in a field related to their disability. Here, we briefly introduce four deaf or hard-of-hearing (D/HH) scientists involved in auditory research: Henry J. Adler, J. Tilak Ratnanather, Peter S. Steyger, and Brad N. Buran, the authors of this article. The first three have been in the field since the late 1980s while the fourth has just become an independent investigator. Our purpose is to relay to readers our experiences as D/HH researchers in auditory neuroscience.

More than 80 scientists with hearing loss have conducted auditory science studies in recent years. They include researchers, clinicians, and past trainees worldwide, spanning diverse backgrounds, including gender and ethnicity, and academic interests ranging from audiology to psychoacoustics to molecular biology (Adler et al., 2017). Many have published in *The Journal of the Acoustical Society of America* (*JASA*), and recently, Erick Gallun was elected a Fellow of the ASA. Recently, approximately 20 D/HH investigators gathered (see **Figure 1**) at the annual meeting of the Association for Research in Otolaryngology (ARO) that has, in our consensus opinion, set the benchmark for accessibility at scientific conferences.

The perspective of scientists who are D/HH provides novel insights into understanding auditory perception, hearing loss, and restoring auditory functionality. Their identities as D/HH individuals are diverse, and their ability to hear ranges from moderate to profound hearing loss. Likewise, their strategies to overcome spoken language barriers range from writing back and forth (including email or text messaging) to real-time captioning to assistive listening devices to sign language to Cued Speech.

Henry J. Adler

Born with profound hearing loss, I was diagnosed at 11 months of age and have since worn hearing aids. I attended the Lexington School for the Deaf in Jackson Heights, New York, NY, and then was mainstreamed (from 4th grade) into public schools (including the Bronx High School of Science) in New York City. When I was at Lexington, its policy forbade any sign language, and listening and spoken language (LSL) was my primary mode of communication. At Harvard College,

Figure 1. *Several of the 80+ scientists with hearing loss discussing their participation at the 2017 Association for Research in Otolaryngology meeting.* ***Standing front to back:*** *Patrick Raphael, Daniel Tward*, Brenda Farrell*^, Robert Raphael^, and Tilak Ratnanather^.* ***Seated, clockwise from left:*** *Erica Hegland, Kelsey Anbuhl, Patricia Stahn, Valluri "Bob" Rao, Oluwaseun Ogunbina, Adam Schwalje, Steven Losorelli, Stephen McInturff, Peter Steyger^ (standing), Lina Reiss^, and Amanda Lauer*^. *, Person is not deaf or hard of hearing;* ***^,*** *person is in the STEMM for Students with Hearing Loss to Engage in Auditory Research (STEMM-HEAR) faculty. Photo by Chin-Fu Liu*.*

Cambridge, MA, my main accommodation was note taking, with occasional one-to-one discussions with professors or graduate students. After college, I have been communicating in both LSL and American Sign Language (ASL), the latter of which enabled me to use ASL interpreters at the University of Pennsylvania, Philadelphia. These accommodations enabled me to complete my PhD thesis under the supervision of James Saunders, focusing on hearing restoration in birds following acoustic trauma.

One of the things I have learned from attending conferences and meetings is that there are often accommodations for preplanned events. However, a major factor for effective scientific collaboration is impromptu conversations with colleagues at conferences. It is impossible to predict when or where these conversations will occur, much less request ASL interpreters. Recent technological advances now include speech-to-text apps for smartphones that could be used for these impromptu scientific discussions, although initial experience shows that these apps may incorrectly translate technical terms.

I have observed my D/HH peers with cochlear implants succeeding because they are better able to participate in discussions, gaining a bigger picture of their scientific interests. This is different from family discussions because my immediate family would always get me involved. Until my marriage to a deaf woman, I was the only deaf member of my immediate family. Also, my nephew Robby has to fight all the time for his parents' attention when his own family is having a discussion even though he has bilateral cochlear implants. He simply does not like to be left out. Nonetheless, I hesitate on having a cochlear implant myself because I am at peace with my disability. Perseverance and tenacity are key to a successful academic career. My primary interest in biology combined with my hearing loss to cement a lifelong interest in hearing research. No matter what happens in the future, it is important that hearing research gains more than one perspective, especially that provided by diverse professionals with their own hearing loss.

J. Tilak Ratnanather

Born in Sri Lanka with profound bilateral hearing loss, I benefited from early diagnosis and intervention (both of which were unheard of in the 1960s but are now common practice worldwide) that led my parents to return to England. At two outstanding schools for the deaf (Woodford School, now closed, and Mary Hare School, Newbury, Berkshire, UK), I developed the skills in LSL that enabled me to matriculate in mathematics at University College London, UK. More recently, I have benefited from bimodal auditory inputs via a cochlear implant (CI) and a digital hearing aid in the contralateral ear.

In the late 1980s, I was completing my DPhil in mathematics at the University of Oxford, Oxford, UK. One afternoon, when nothing was going right, I stumbled on a mathematical biology seminar on the topic of cochlear fluid mechanics. An hour later, I knew what I wanted to do for the rest of my life. I first did postdoctoral work in London, which gave me an opportunity to visit Bell Labs in Murray Hill, NJ, in 1990. This enabled me to attend the Centennial Convention of the Alexander Graham Bell Association for the Deaf and Hard of Hearing (AG Bell) in Washington, DC. There I heard William Brownell from Johns Hopkins University (JHU), Baltimore, MD, discuss the discovery of cochlear outer hair cell electromotility (see article by Brownell [2017] in *Acoustics Today*). A brief conversation resulted in my moving to JHU the following year to work as a postdoctoral fellow with Brownell.

It was at this convention that I came across a statement in the Strategic Plan of the newly established NIDCD (1989, p. 247).

> "The NIDCD should lead the NIH in efforts to recruit and train deaf investigators and clinicians and to assertively pursue the recruitment and research of individuals with communication disorders. Too often deafness and communication disorders have been grounds for employment discrimination. The NIDCD has a special responsibility to assure that these citizens are offered equal opportunity to be included in the national biomedical enterprise."

This enabled me to realize that I could become a role model for young people with hearing loss. Meeting Henry and Peter cemented my calling. My research in the auditory system began with models of cochlear micromechanics and now focuses on modeling the primary and secondary auditory cortices. I also mentored students and peers with hearing loss in STEMM. In 2015, these efforts were recognized with my receiving a Presidential Award for Excellence in Science, Mathematics and Engineering Mentoring (PAESMEM) from President Obama.

Today, more young people who benefited from early diagnosis and intervention with hearing aids and/or cochlear implants are now entering college. Many want to study the auditory system to pay forward to society. The PAESMEM spurred me to establish, with the cooperation of AG Bell, STEMM for Students with Hearing Loss to Engage in Auditory Research (STEMM-HEAR; deafearscientists.org) nationwide. In recent summers, students worked at the Oregon Health and Science University, Portland; Stanford University, Stanford, CA; the University of Minnesota, Minneapolis; the University of Southern California, Los Angeles; and JHU. STEMM-HEAR exploits the fact that hearing research is at the interface of the STEMM disciplines and is a perfect stepping stone to STEMM. STEMM-HEAR is now exploring at how off-the-shelf speech-to-text technologies such as Google Live Transcribe and Microsoft Translator can be used to widen access in STEMM (Ratnanather, 2017).

Peter S. Steyger

Matriculating into the University of Manchester, Manchester, UK, in 1981 was a moment of personal and academic liberation. Higher education settings had seemingly embraced diversity, however imperfectly, based on academic merit. Finally, I could ask academic questions without embarrassing teachers lacking definitive answers. Indeed, asking questions where answers are uncertain or conventional wisdom insufficient led to praise from professors and the confidence to explore further, particularly via microscopy in my case. Nonetheless, I remained a "solitaire," the only deaf undergraduate in the zoology class of 1984 and indeed of all undergraduates in biological sciences between 1981 and 1984.

One strategy deaf individuals using LSL use is to read voraciously (to compensate for missed verbal information), and I had subscribed to *New Scientist.* An issue in 1986 invited applications to investigate ototoxicity (the origin of my own hearing loss as an infant) using microscopy under the direction of Carole Hackney and David Furness at Keele University, Staffordshire, UK. That synergy of microscopy, ototoxicity, and personal experience was electrifying and continues to this day. This synergy also propels other researchers with hearing loss to answer important questions underlying hearing loss. These answers need to *make rational sense* and not just satisfy researchers with typical hearing who take auditory proficiency for granted. As our understanding of the mechanisms of hearing loss grows, the more we recognize the subtler ways hearing loss impacts each of us personally or those we hold dear as well as society in general. Accessibility and effective mentorship are vital for inclusion and growth during university and postdoctoral training.

I now experience *age-related hearing* because new hearing technologies are personally adopted and am currently bimodal, using a CI in one ear and connected via Bluetooth to a hearing aid in the other. Each technological advance enabled the acquisition of new auditory skills, such as sound directionality and greater recognition of additional environmental or speech cues, contrasting with peers with age-related hearing loss unable or unwilling to adopt advances in hearing technology. Each advance in accessibility, mentorship, and technology accelerates the career trajectories of aided individuals. With the acquisition of each new auditory skill, I marvel anew about how sound enlivens the human experience.

Brad N. Buran

My parents began using Cued Speech with me following my diagnosis of profound sensorineural hearing loss at 14 months of age. Cued Speech uses handshapes and hand placements to provide visual contrast between sounds that appear the same on the lips. Because Cued Speech provides phonemic visualization of speech, I learned English as a native speaker. Although I received bilateral cochlear implants as a young adult, I still rely on visual forms of communication to supplement the auditory input from the implants.

Interested in learning more about my deafness, I studied inner ear development in Doris Wu's laboratory at the National Institute on Deafness and Other Communication Disorders (NIDCD), Bethesda, MD, as an intern during high school.

This was followed by an undergraduate research project on the inner ears of deep-sea fishes in Arthur Popper's laboratory at the University of Maryland, College Park. These early experiences cemented my interest in hearing research, driving me to pursue a PhD with Charles Liberman in the Harvard-MIT Program in Speech and Hearing Bioscience and Technology, Cambridge, MA.

Although my graduate classmates were interested in Cued Speech, most assumed they would not have time to learn. Realizing that Cued Speech is easy to learn, one classmate taught himself to cue over a weekend. Being a competitive group, my other classmates learned how to cue as well. I truly felt part of this group because I could seamlessly communicate with them.

Many of my peers in auditory science are interested in my experience as a deaf person. Their questions about deafness are savvier than those I encounter on the street. For example, the speech communication experts ask detailed questions about Cued Speech (e.g., how do you deal with coarticulation?). The auditory neuroscientists who dabble in music try to write a custom music score optimized for my hearing.

As a deaf scientist, communication with peers is a challenge. Scientists often have impromptu meetings with colleagues down the hall. If I cannot obtain an interpreter, I have to rely on lipreading and/or pen and paper. Fortunately, the Internet has significantly reduced these barriers. Most scientists have embraced email and Skype as key methods for communicating with each other. In my laboratory, we use Slack, a real-time messaging and chatroom app for most communications. Likewise, the availability of cloud-based resources for teaching has streamlined the programming in the neuroscience course I teach. Although I still use interpreters during classes, the availability of email and online chatrooms has allowed me to hold "virtual" office hours without having to track down an interpreter each time a student wants to meet with me. In addition to advances in technology, the advocacy of my senior D/HH colleagues has lowered barriers by increasing awareness of hearing loss in academia and ensuring that conferences are accessible to researchers with disabilities.

Take-Home Message

Researchers with hearing loss, regardless of etiology, bring many benefits to auditory sciences. Their training and vocabulary enable more accurate, real-world descriptions of auditory deficits, advancing knowledge in auditory sciences and stimulating research into mechanisms and implications of auditory dysfunction. Their interactions with hearing researchers provide teachable moments in understanding the real-world effects of hearing loss. The ability to succeed in research requires resilience and perseverance. This is particularly true for individuals with disabilities who must overcome additional barriers. When provided with the resources they need and treated with the respect and empathy that all individuals deserve, they can make remarkable contributions to STEMM, especially in the auditory sciences.

More importantly, these researchers are changing perceptions about how those with disabilities can integrate with mainstream society. However, this integration is not automatic. The maxim espoused by George Bernard Shaw (1903), "The reasonable man adapts himself to the world; the unreasonable one persists in trying to adapt the world to himself," remains pertinent. The ability to recognize new and emerging technological advancements and utilize creative strategies in adapting to one's own disability leads to a greater quality of life and more successful careers regardless of profession.

Last but not least, we would very much appreciate readers to encourage colleagues, staff, and trainees with hearing loss to join our expanding group (deafearscientists.org). Increased visibility and contributions by those with hearing loss can only enhance advances by the field as a whole!

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