

## Let's Talk

BY RICHARD EINHORN

Let's talk about race and hearing loss. I've wanted to do so for a long time, and recent events have only made it a more pressing topic. But because the National Academies of Sciences, Engineering, and Medicine's groundbreaking study on hearing health care for adults found that "only limited evidence is available on the use of hearing health care services by low-income adults and racial and ethnic minorities," I reached out directly to members of the African American hearing health community for their thoughts and comments.

I first spoke to audiologist Sharon W. Williams, Ph.D., CCC-A, an associate professor and director of the Division of Speech and Hearing Sciences at the University of North Carolina at Chapel Hill. I asked Dr. Williams about research that suggests that the



prevalence of hearing loss among people of color may be lower than among whites. "I'm aware of those studies, but I'm not sure how true it is. If we think about children born with hearing loss, there's not really a reason to believe that fewer children are born with hearing loss because of race."

As for adults, Dr. Williams said that it might not be that hearing loss prevalence is necessarily lower, but rather that "fewer people of color come to our clinics, and we aren't often going to [their] communities, either. In addition, fewer people of color participate in research studies. There are people out there [who] could benefit from our services, but they're just so much less likely to get it. I often say that it's a justice issue." She sighed. "So often insurance doesn't pay. Or there are no audiologists [in the area] or the people who need help are just not sure how to navigate the system."

Dr. Williams also pointed to another issue. "Only about 3% of audiologists in the U.S. are Black," she said. "It's stunning. This likely impacts the number of underrepresented students in our programs. Another

key contributor is the financial costs and potential debt associated with a doctorate degree."

Dr. Williams pointed to an even deeper problem: "I think there's some implicit bias as well." She suggested that audiology programs should do more "to make sure all of our students feel included and welcomed and that we expect them to succeed." To address the situation, Dr. Williams and her colleagues at Chapel Hill "engage in targeted efforts to reach underrepresented students to let them know about our programs. We also participate with the National Black Association for Speech-Language and Hearing," ([nbaslh.org](http://nbaslh.org)) which addresses "the communication interests and concerns of Black communication science and disorders professionals, students and consumers." I am pleased to see that other audiology organizations and programs are also making more effort toward inclusion and equity.

Next, I spoke to two members of the HLAA Virginia Beach Chapter. Angela P. Hill was first diagnosed as a young child with a mild-to-moderate hearing loss and received her first hearing aid at the age of six. That led to a discovery. "I got in the car," she said. "My mom had on some music, and the first thing I did was bebop to the music!" She quickly developed a love for the piano and went on to major in music and teach piano. Her hearing began to get worse in college but she "pushed through," got her degree in music education, and continued to teach piano. However, her hearing continued to decline and for 20 years, she had to stop playing.

Finally, in 2012, Angela got a cochlear implant (CI) in her right ear, followed by another implant for her left ear in 2015. The CIs were "a game changer in my life," she said, and she returned to her piano playing. During our video calls, she even treated me to some wonderful live performances. I'm looking forward to more!

Angela described an alarming situation for anyone with hearing loss, one made more so for many members of the Black community. Before she received her CIs, Angela's husband was driving the two of them home to Virginia from North Carolina. Using cruise control, he was strictly observing the speed limit when they passed a state trooper. A few minutes later, "we see these blue lights. It must have been another police officer, we don't know where he came from," and they were pulled over. They were on a major route "where there were fields to the right of us." Her husband was polite but insistent, asking why he was stopped. Angela had to rely only on lipreading to understand what was going on.

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She tried to signal her husband: “‘Don’t ask questions, just give him what he wants.’ All I could think of was the worst-case scenario. This police officer is going to pull my husband out of the car in this field out in the middle of nowhere.”

“I got scared,” Angela said, “Thankfully, he didn’t do anything, he just wanted to look at my husband’s driver’s license.” But Angela was left feeling shaken. Reflecting on the incident, she wonders whether racial profiling was involved. About a year later, at the HLAA Chapter meeting, Angela picked up a placard to place in her car explaining that she has hearing loss “in case we ever get stopped again and the police get upset as to why I’m not responding.”

Angela introduced me to Ronette Jacobs, an assistant professor of English at Camp Community College in Suffolk, Virginia. In 2009, Ronette was meditating when she suddenly heard an “ocean sound.” Her ear, nose and throat specialist ordered an MRI, which revealed acoustic neuromas on the auditory nerves of both of Ronette’s ears. In 2013, after one of the tumors had grown considerably, she had a craniotomy to remove the tumor on her right side. There was no choice but to sever the auditory nerve, which left her completely deaf in her right ear. In 2015, the tumor came back, and she underwent radiation therapy, losing 50-60% of her hearing in her left ear.

To stay connected to her life and career, Ronette has been remarkably resourceful. For phone and video calls, she relies on captioning services. In order to continue teaching, Ronette uses Cros hearing aids and an FM microphone, which the students pass around. She also deploys transcription software and even makes note cards available for every row of students where they can write down their questions for her.

Ronette is both matter-of-fact and clear about the challenges she’s faced. “There was one level of invisibility that I experienced as a Black woman. Having hearing loss—that’s another level of invisibility, because some people feel that communication is complicated and don’t want to participate.”

She spoke eloquently about the stigma of hearing loss in the African American community, of the significant lack of decent captioning in some films made for Black audiences and the absence of Black representation in audiology and other areas of hearing health. “HLAA needs to hear our story,” she said. “Educate, inform and empower. Our story is going to be a little bit different.”

One way the story of African Americans with hearing loss is “a little different” is that many fewer Black people can afford hearing aids than whites. The median household income for hearing aid owners (\$60,400) was far higher than that of Black households (\$41,361).

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Thirty years ago, HLAA collaborated with congressional leaders to include hearing access in the Americans with Disabilities Act (ADA), legislation that made it clear that the lives of people with disabilities matter. Even so, people of color who have hearing loss remain underrepresented and underserved in the hearing health community. That can, and should, change.

Special thanks to Erin Picou, Au.D., research assistant professor, Vanderbilt University; past HLAA Board Chair Don Doherty; HLAA Board Member Carrie Nieman, M.D.; and Carole Rogin, strategic adviser to the Hearing Industries Association, for their kind help with this column. **HL**

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