

Reaching Out: Supporting Doctors in Learning About the Deaf Community

By Debra Nussbaum, Lauri Rush, Carla Shird, and Catherine Martin-Davis

The incidence of infants who are born deaf or hard of hearing in the United States is between 1 and 3 in 1,000 births (Centers for Disease Control and Prevention, 2013). This incidence of hearing loss increases significantly as a child gets older, and by the time a child is school-aged, it is estimated that 9 to 10 in 1,000 children will be identified as deaf or hard of hearing (American Academy of Audiology, 2011). Additionally, approximately 15 percent of American adults (37.5 million people) aged 18 and over report hearing challenges (National Center on Deafness and Other Communication Disorders, 2016).

Doctors typically have limited experience working with patients who are deaf or hard of hearing. This is in part related to the low incidence of infants born deaf or hard of hearing and the low—but increasing—percentage of children and adults with hearing loss. When doctors do have experience and training with deaf and hard of hearing individuals, it generally focuses on the medical aspects of hearing (e.g., evaluating hearing, facilitating and restoring hearing through hearing aids and cochlear implants). As a result, repeated pleas have gone out for the medical community to better understand the nonmedical needs of deaf and hard of hearing individuals, especially from parents and educators of deaf and hard of hearing children.

Unfortunately, limited opportunity exists for medical students and doctors to learn what is involved in working with deaf and hard of hearing patients and what is necessary to know in raising and educating a child who is deaf or hard of hearing. Only a few medical training programs and continuing education programs infuse information about the cultural, linguistic, cognitive, social-emotional, and educational aspects of being a deaf or hard of hearing person with the medical aspects of hearing—and one of them is Howard University Medical School in Washington, D.C. Partnering with Gallaudet University, Howard medical students have had the opportunity to interact with deaf and hard of hearing professionals and to learn the unique needs of the Deaf community.

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Lauri Rush, PsyD, has been the director of Counseling and Psychological Services at Gallaudet University since 1995. She has worked as a licensed clinical psychologist with deaf and hard of hearing children as well as with families and adults at the California School for the Deaf-Fremont and at Gallaudet University. Her areas of interest and expertise include family therapy, clinical supervision, ethics in mental health, and crisis management. Rush is the parent of a deaf 15-year-old daughter.

Photos by Matthew Vita



Above: Carla Shird, from Gallaudet's CAPS team, sets up the agenda for the day.

While expanding the curriculum of every medical school would be ideal, evidence has shown that even a one-day training on deaf awareness and communication can have a positive impact on how doctors support their deaf and hard of hearing patients (Humphries et al., 2014). The training that Gallaudet University developed with Howard University can serve as a model for other educational programs throughout the country that are interested in reaching out and partnering with medical schools and doctors. Initiation of such a program has the potential to improve medical service provision to individuals who are deaf or hard of hearing and their families.

Doctors in Training Come to Learn The Gallaudet/Howard Experience

Gallaudet's Counseling and Psychological Services (CAPS) and Howard have partnered to train medical students for many years. At the most recent training, 35 medical students came to the Gallaudet campus for a workshop on providing quality care to deaf and hard of hearing individuals and the Deaf community. At the workshop, Howard's students interacted

with deaf and hard of hearing professionals and experienced communication through American Sign Language (ASL). They learned about the importance of using culturally sensitive terminology; considerations for counseling families related to language acquisition; realistic expectations for use of listening technologies, including cochlear implants; and considerations for using a sign language interpreter.

As the doctors in training participated in the workshop, they learned about the social, cultural, educational, and psychological implications of being deaf or hard of hearing—and how they could best support their deaf and hard of hearing patients. A hearing parent of a deaf child—who is also a professional within Gallaudet's counseling program—and a deaf professional added important personal dimensions to the training. A role-playing activity concluded the training, simulating a doctor's experience with a deaf patient and providing an opportunity to apply much of the information discussed.

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Catherine Martin-Davis, MA, LPC, RPT-S, has been a mental health counselor in Counseling and Psychological Services at Gallaudet University since 2015. She has worked in the mental health field for over 20 years and has experience working with deaf, hard of hearing, and hearing individuals in clinics, hospitals, and school settings. In addition, Martin-Davis is a board-approved supervisor in Maryland and a registered play therapist supervisor; she has recently started in private practice.

The authors welcome questions and comments about this article at lauri.rush@gallaudet.edu.



Left: Approximately 35 Howard University medical students participate in a four-hour workshop entitled “Providing Quality Medical Care to the Deaf Community.”

What We Need to Tell Medical Professionals Five Points for Improving Care

The points below are part of a model that deaf educators can use in reaching out to the medical community. If medical professionals can do the following, it may improve the level of care for deaf and hard of hearing individuals.

1. Share information in culturally sensitive language.

It was extremely informative to see how using different words can change ... how a parent feels.

- comment from a workshop participant

Doctors need to understand the importance of sharing information in a positive, supportive manner rather than in an apologetic manner that conveys hopelessness and despair. This is especially important when a newborn baby is found to be deaf or hard of hearing. When a respected doctor conveys hope and potential, families are more apt to feel positive about their child’s future. How information is shared is sometimes as important as what information is shared, and using culturally sensitive terminology is important. For example, many deaf and hard of hearing individuals feel that using the term “hearing impaired” emphasizes a pathological view of a person. Describing a person instead as “deaf” or “hard of hearing” provides terminology that is part of a deaf individual’s cultural perspective.

2. Recognize and share the importance of immediate language access.

Are there many professionals who are “purists” in their recommendations about language acquisition (only supporting either signed language or spoken language)?

- question from a workshop participant

While there may be professionals who counsel families to use either signed or spoken language, it may not be in the best interest of the child to do one or the other. Doctors are in the position of advising families about the linguistic aspects of their child’s development, and it is therefore important that they take an active role in sharing with families the critical importance

of immediate and full access to language in the most accessible way possible. To this end, doctors should encourage families to explore the benefits of facilitating language acquisition visually through ASL while also fitting the child for listening technologies and exploring spoken language. Doctors need to know that partial access to a language is not enough to learn it effectively; that benefits accrue to children who are bilingual in ASL and English; and that, just as important, children can and do master both languages successfully.

Doctors can help parents see the connection between their child’s timely language acquisition—either signed or spoken—and their child’s linguistic, cognitive, and social health. Further, doctors and other members of the medical community should learn about the important asset of the Deaf community and how interaction with deaf and hard of hearing adults can add insight and joy to the journey of raising a child who is deaf or hard of hearing.

3. Discuss the varied outcomes resulting from the use of technology.

What is the Deaf community perspective about cochlear implants?

- question from a workshop participant

While doctors and medical professionals may receive general information about hearing aids and cochlear implants, they often do not learn the varied effects of these devices on the lives of deaf and hard of hearing people. These effects include fitting and maintaining hearing aids and implants and the highly individualized benefit each person receives from them. Ideally, doctors should understand and convey that listening technologies are only part of the continuum of supports recommended for children who are deaf or hard of hearing.

When counseling families about cochlear implants, doctors need to look beyond the surgery and discuss the effects of the

implant on an individual's life. These include:

- varied outcomes in spoken language
- importance of consistent use
- necessity of training
- cultural perspectives of the Deaf community
- day-to-day considerations (e.g., paying for batteries, returning to the hospital for programming of the external components of the implant, coping when external parts of the implant are not working, the possibility of internal device failure)

Doctors and clinicians should be aware of and be able to counsel families about realistic expectations and recommended supports to promote language acquisition and learning of a child using cochlear implant technology. This may mean countering the misguided belief that children with cochlear implants should not sign and sharing evidence about the benefits of a child becoming bilingual, whether the child's languages are both spoken or one is signed and one is spoken (Davidson, Lillo-Martin, & Chen Pichler, 2014).

4. Understand that being deaf or hard of hearing impacts social-emotional health.

It really hit me when I needed something in the Gallaudet bookstore, how I had to think about how I was going to communicate what I needed.

~ comment from a workshop participant

Being deaf or hard of hearing is not just about the physical process of hearing but also about the social-emotional aspects of being a deaf or hard of hearing individual. People who are deaf or hard of hearing often share experiences of being left out of conversations, feeling isolated, and being bullied. It is important that doctors are familiar with the many interwoven factors involved in the social health of individuals who are deaf or hard of hearing and are aware of possible red flags to look for which might indicate that the attention of mental health providers is required. In addition, advice from a medical practitioner emphasizing the healthy benefits of being involved in the Deaf community can go a long

Right: Shird teaches medical students the ASL sign for "doctor."

Access to quality medical care for individuals begins with a fluent and trusting flow of communication between the patient and physician.

way in supporting positive social-emotional health.

5. Provide access to communication.

Do you think doctors are thorough enough with deaf patients ... or do they abbreviate and gloss over information?

~ question from a workshop participant

Access to quality medical care for individuals begins with a fluent and trusting flow of communication between the patient and physician. It is therefore critical that the medical community understands how to provide effective access to communication for the deaf and hard of hearing patients within their practice. This includes understanding the pros and cons of various interpreting options as well as the ethics and

confidentiality involved in using an interpreter. Doctors should communicate with patients who are deaf or hard of hearing as they would with any patient; abbreviating information should never be an option. Patient communication and care should not be impacted by an individual's hearing status.

Get Involved Set Up a Training in Your Community

Families of children who are deaf or hard of hearing, like families of all children, look to their doctors for guidance in making decisions about their child. The Deaf educational community has the knowledge and experience to work with doctors, medical students, and clinicians to make a positive impact on the medical care received by individuals who are



Right: Medical students role play real-life scenarios working with deaf and hard of hearing patients.

deaf or hard of hearing.

Look for opportunities to offer workshops in your area. Invite staff from local hospitals or local medical practitioners to activities such as a “lunch and learn” at your school or agency. Follow the lead of Gallaudet and make outreach to medical practitioners a goal. When given the opportunity for education and training, doctors can be on the front lines of improving not only access to care and medical outcomes but also social and academic outcomes—and the quality of life for deaf and hard of hearing individuals.



References

American Academy of Audiology. (2011). *Childhood hearing screening guidelines*. Retrieved January 24, 2018, from https://www.cdc.gov/ncbddd/hearingloss/documents/aaa_childhood-hearing-guidelines_2011.pdf

Centers for Disease Control and Prevention. (2013, September). *Summary of 2011 national CDC EHDI data*. Retrieved January 24, 2018, from https://www.cdc.gov/ncbddd/hearingloss/2011data/2011_ehdi_hsf_s_summary_a.pdf

Davidson, K., Lillo-Martin, D., & Chen Pichler, D. (2014). Spoken English language development in native signing children with cochlear implants. *Journal of Deaf Studies and Deaf Education*, 19, 238-250.

Humphries, T., Kushalnagar, P., Mathur, G., Napoli, D., Padden, C., Pollard, R., ... & Smith, S. (2014). What medical education can do to ensure robust language development in deaf children. *Medical Science Educator*, 24(4), 409-419. doi 10.1007/s40670-014-0073-7

Joint Committee on Infant Hearing. (2007). Year 2007 position statement: Principles and guidelines for Early Hearing Detection and Intervention programs. *Journal of Pediatrics*, 120(4), 898-921. Retrieved January 24, 2018, from <http://pediatrics.aappublications.org/content/pediatrics/120/4/898.full.pdf>

National Center on Deafness and Other Communication Disorders. (2016, December). *Quick statistics about hearing*. Retrieved January 24, 2018, from <https://www.nidcd.nih.gov/health/statistics/quick-statistics-hearing>

Resources

American Academy of Pediatrics. (2018). *Early Hearing Detection and Intervention (EHDI)*. Retrieved January 24, 2018, from <https://www.aap.org>

Lytle, L. R., & Oliva, G. (2016). *Raising the whole child: Addressing social-emotional development in deaf children* (Research Brief No. 11). Washington, DC: Science of Learning Center on Visual Language and Visual Learning, Gallaudet University.

Solomon, A. (2012). *Far from the tree: Parents, children and the search for identity*. New York: Simon & Schuster.