

8 Tools to Reduce the Impact of Stigma

By Holly Cohen and Nancy M. Williams

Stigma exists in your external environment, but it can also manifest from inside of you in the messages that you tell yourself. Consider making changes in your life to reduce stigma by committing to at least one of the following tools:

Tool #1: Take responsibility for your hearing loss. Accept your hearing loss and resist the urge to deny it. In most cases, your hearing loss is not the secret you think it is. Commit to wearing your hearing aids or cochlear implant(s) every day to hear better. Visit your audiologist for adjustments to ensure that your devices are working well.

Tool #2: Create and adopt new messages about your hearing loss. Get a better understanding of how internal and/or external stigma manifests in your life. Determine which voices in your head belong to you—and which ones belong to other people. Focus on what you can control. If you feel “less” because of your hearing loss, alter the message that you tell yourself by changing “I can’t” statements to “I can.” Accept that the hearing loss is one part of you but it’s not all of who you are.

Tool #3: Make a list of difficult listening situations. Reflect on each day of the week and make a list of challenging listening situations organized by home, work, and public places. Be specific and note what you’re feeling—uncomfortable, vulnerable, embarrassed, or ashamed. If a situation triggers an unhappy memory from the past, add the memory to your list.

Tool #4: Plan how to talk about your hearing loss. If your hearing aid or cochlear implant is visible, your hearing loss is probably not a secret. If your device is not visible, other people such as your family, friends, and co-workers might not know about your challenges with hearing clearly. In either situation, it takes courage to accept your hearing loss and no small amount of bravery to talk about it. Plan what you want to say. Consider practicing out loud with someone you trust.

Tool #5: Ask for accommodations. Technology is ever-changing. Educate yourself about the range of assistive listening devices so that you can identify and request the appropriate




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technology and accommodations that you need. People in your life may not know what is available or appropriate for your condition. Become the expert, then ask. Learn about not only technical solutions but also non-technical strategies like note-taking buddies at work.

Tool #6: Communicate effectively and comfortably. How you handle your hearing loss will have a direct impact on the people you closely and regularly interact with. Teach the people in your life how to best communicate with you so that you can hear clearly. For example, remind them to face you when they speak. Your hearing difficulties can be as new and challenging for them as they are for you. Ask speakers to repeat their point in a different way. Remember that humor goes a long way to increase comfort for everyone.

Tool #7: Set realistic and meaningful goals. Living well with hearing loss requires change and adaptability. Change happens slowly and requires commitment. Don’t take on more than is reasonable and consider your other responsibilities. However, make a commitment to a meaningful and achievable goal to reduce the effects of stigma on your life.

Tool #8: Connect with other people with hearing loss. The challenges of living with hearing loss and ways to overcome them are known best by those who live with it. Consider participating in online forums and connecting with local hearing loss advocacy groups and events to meet people who “get it” (e.g., AG Bell Association for the Deaf and Hard of Hearing, Association of Late Deafened Adults, Hands & Voices, Hearing Health Foundation, and Hearing Loss Association of America, among others). Engaging in these communities and events can help you be yourself and learn from others who understand the impact of living with hearing loss. 



Ms. Cohen, left, is a hearing health advocate and speaker who has been impacted by stigma, professionally and personally, while living with hearing loss for decades. **Ms. Williams** is a strategic management consultant, advocate, and speaker in hearing health care, with expertise in

new market development, patient engagement, and consumer insight.



FAST READ:

Studies point to a host of poor health outcomes for patients with untreated hearing loss, including higher comorbidity, hospitalization rates and health care costs. Needed remedies for these patients include improved access to amplification devices, increased referrals for hearing screenings, and more attention to their communication needs from providers.

UNTREATED, UNINFORMED AND POWERLESS

Joe struggled to follow what his primary care provider and wife said during a consultation about Joe's high blood pressure, heart disease and asthma. "What? What was that?" he asked multiple times. Finally, Joe's wife spoke up, saying Joe had not been able to hear well for years. Joe quickly defended himself. He had already met with an audiologist who confirmed his hearing loss. However, he ignored the audiologist's recommendation to get fitted with hearing aids since he couldn't afford to pay several thousand dollars for the devices.*

Joe had retired early from his job as a teacher due to his worsening hearing loss. Ever since, he'd faced financial and health woes. To make matters worse, Joe felt isolated from his friends and family because of his hearing loss. Joe's wife was concerned that Joe had been declining physically, emotionally and socially since retiring early. She was frustrated with the lack of options to help Joe.

Unfortunately, Joe's situation is far from unusual. Hearing loss is common, affecting more than 15 percent of Americans ages 18 and older, according to 2012 National Health Interview Survey data. And a data analysis we published last year in the *Disability and Health Journal* with Amanda Reichard reveals that adults with hearing loss commonly have chronic diseases such as cardiovascular disease and diabetes, as well as poorer self-reported health, than peers without hearing loss (bit.ly/diseases-hearing). This leads us to speculate that hearing loss may factor into a heavier disease burden.

Our findings square with past research that also links hearing

loss to poor health care access and outcomes. Patients with hearing loss are more likely to be hospitalized and readmitted within 30 days for the same condition, and also to report poorer communication and satisfaction during medical care encounters, as found by researchers such as Ji Eun Chang (bit.ly/hearing-hospital).

Not surprisingly, these outcomes result in higher health care costs for patients with hearing loss. Per-person spending is as much as \$22,000 higher over 10 years when compared to those with normal hearing, even after adjusting for a variety of sociodemographic and health factors, as per findings in a 2018 JAMA Otolaryngology-Head

and Neck Surgery article (bit.ly/JAMA-HLcosts).

What can be done to improve access and outcomes for this vulnerable population? One remedy is to reduce the high cost of hearing aids, which makes hearing treatment prohibitive for patients like Joe. Congress has passed legislation to make this happen by allowing hearing devices to be sold over the counter (see the Leader article, “OTC Hearing Legislation Becomes Law: What’s Next?” on.asha.org/OTC-future).

The U.S. Food and Drug Administration (FDA) is expected to issue regulations for OTC hearing aids in 2020. Meanwhile, those who can afford them can opt to purchase personal sound amplification products (PSAPs)—over-the-counter devices not FDA-approved and intended only for use with mild-to-moderate hearing loss for people older than 18 (see the Leader article, “Add PSAPs To Your Practice?” on.asha.org/PSAP-practice).

Beyond promoting use of amplification devices, audiologists, speech-language pathologists and other providers can help bolster patients’ access to hearing health in other ways: advocating for and conducting hearing screenings, educating others about behavioral techniques to improve communication with people with hearing loss, and noting patients’ hearing loss and communication needs in patient documentation.

Let’s delve further into what drives hearing health disparities, and what can be done to equalize care.

UNEQUAL ACCESS

In our Disability Health Journal study, we analyzed data on 53,111 National Health Interview Survey participants, ages 65 and older. We found that respondents with hearing loss were more likely to experience arthritis, cancer, cardiovascular disease, diabetes, emphysema, high blood pressure and stroke than respondents without hearing loss. Older patients with hearing loss also rated their health more poorly than did age-matched peers without hearing loss.

In addition to the higher association with physical disease that we found, other studies tie hearing loss to problems with mental health, cognitive functioning and activities of daily living (see sources). Achieving good health is further complicated because people with hearing loss are less likely to be employed and are more often lower-income than people without hearing loss (see sources). As a result, they often rely on public insurance, which makes finding health care providers more difficult—not all providers participate in public plans, because reimbursement rates are lower than private insurance.

There is, however, reason to hope that people with hearing loss can have good health and medical care outcomes. Those who gain access to hearing aids fare better medically

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than their peers without hearing aids, including an 8-percent lower relative risk of having an emergency visit and 9-percent lower relative risk of having a hospitalization—as found in research led by Elham Mahmoudi (bit.ly/HA-healthcare).

Spurred by such findings, in 2016 a committee of the National Academies of Science, Engineering, and Medicine recommended changes to improve health care access for people with hearing loss (bit.ly/HHC-adults). The Committee on Accessible and Affordable Hearing Medical Care for Adults' principal recommendation was to make hearing aids and hearing devices easier to access. To put the committee's recommendation into practice, Congress passed the Over-the-Counter Hearing Aid Act of 2017. The FDA is developing regulations to implement that law. In the meantime, the FDA has approved Bose "self-fitting hearing aids" for over-the-counter sales for people with mild to moderate hearing loss (on.asha.org/ldr-bose-otc).

The OTC Hearing Aid Act will likely benefit a large portion of people with milder hearing loss who've been priced out of the market. However, it may not help people with more severe forms of hearing loss—whose access to hearing aids will not change under the new regulations—and

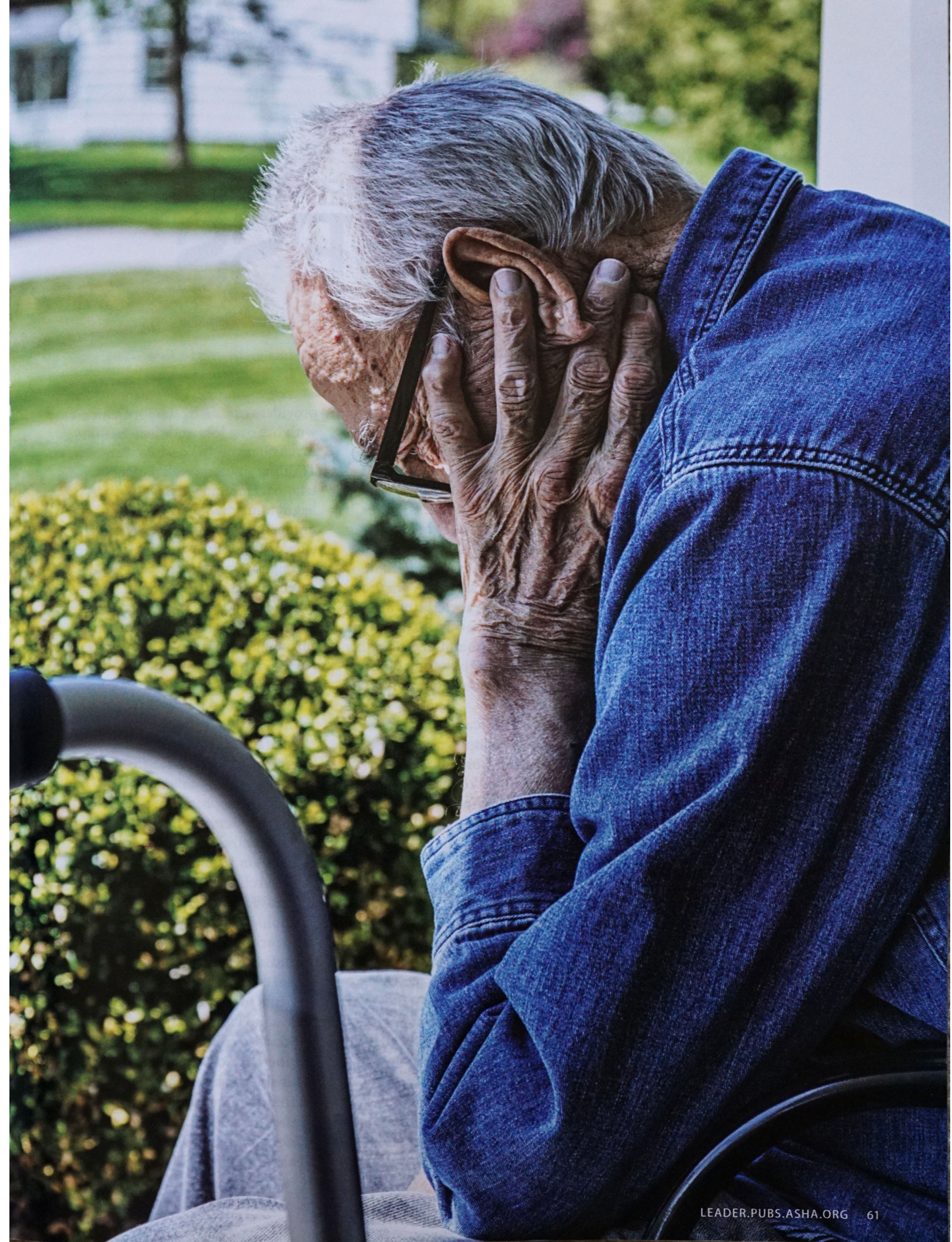
those already with low income and reduced access to health care.

Costs for a pair of hearing aids vary widely, from \$1,200 to \$7,000, with costs for fitting, programming and rehabilitation sometimes included or added separately. Compounding the cost is the fact that health insurance plans, including Medicare, rarely include any hearing aid coverage, resulting in significant out-of-pocket costs. It's no surprise that only 14 percent of U.S. adults 50 years and older with hearing loss use hearing aids (see sources).

RESEARCH CHALLENGES

Although there is a growing literature on the health and health care outcomes associated with hearing loss, there is still much work to do. For example, one important source of research information is medical claims data, but hearing loss is poorly captured in these data. Even if hearing loss diagnosis codes (such as International Statistical Classification of Diseases and Related Health Problems [ICD]-9 and 10 codes) are used, medical care providers frequently select "hearing loss, unspecified." This classification limits researchers' ability to determine how worsening hearing loss may affect health and health care.

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When primary care providers *do* select hearing-loss codes, they choose codes that likely reflect more severe forms of hearing loss, not milder ones, that affect ability to deliver care. This practice likely biases the reported findings associated with hearing loss and leads to policy and practice recommendations that don't align with patients' needs and providers' experiences.

But there's been an important and helpful development on the data-collection front: Thanks to a stipulation in the Patient Protection and Affordable Care Act of 2010, all federally funded surveys must now include a core set of disability questions, including one identifying people with hearing loss (see "Communication: It's Critical to Care" on page 46). With this addition, researchers can more consistently identify and track hearing loss across the U.S., furthering the development of policies and programs to support people with hearing loss.

PRACTICAL STEPS TO BOOST ACCESS

As the FDA works up its proposed OTC rules, there is much that audiologists, SLPs and other

providers can do to support patients with hearing loss and their health care colleagues who serve them. Training to work with patients who have hearing loss should begin in medical school and in graduate school for other health care professions, and continue throughout providers' training and career. Indeed, federal regulations require that health care facilities ensure effective communication through auxiliary aids and services.

Here are some specific actions providers can take to improve health care access and services for patients with hearing loss:

Push for hearing screening whenever applicable. Screening rates for hearing loss are poor (see sources), prompting the U.S. Preventive Services Task Force to recommend that all patients older than 49 and at risk for hearing loss be screened, and subsequently diagnosed and given services. Audiologists can guide patients on hearing amplification options, including hearing aids and PSAPs, as needed, and SLPs can refer patients to audiologists for this follow-up care.

Educate colleagues on the importance of capturing hearing loss in medical records. Better documentation will help researchers develop a more accurate understanding of the health and health care needs of these patients

and tip off medical providers and support personnel about the need to use supportive communication strategies and/or provide an interpreter during visits (see “Are Your Patients *Really* Hearing You,” on.asha.org/ldr-pts-hear).

Work with medical administrators to hold workshops and trainings on effective communication strategies with people with hearing loss (such as facing and making eye contact with patients when speaking and using clear speech). This step will not be easy, as budgets and personnel are strained throughout health care organizations. But it is important work, especially to comply with the law.

Advocate for use of PSAPs at health care facilities. Some clinics provide in-office PSAPS to patients with untreated hearing loss, to aid their communication with health care team members (see “Amplifying Patient Care,” on.asha.org/Pitt-PSAP). Providing such accommodations helps facilities comply with the Americans With Disabilities Act. Audiologists and SLPs can also guide patients on other hearing assistive tools, such as smartphone applications, to help them manage everyday tasks and navigate life.

Hearing loss is a recognized risk factor for dementia and, as we found, is also common among older people with chronic conditions. Managing chronic conditions and maintaining good health and social participation are complex for these

patients. All health care providers play a role in ensuring that their patients with hearing loss can understand and act on health care recommendations.

As Joe’s story reveals, patients may be unable to access hearing devices for financial reasons, but that alone should not be a barrier to good health care outcomes. With increased attention to communication and amplification options—including more devices offered to patients for use during appointments—patients like Joe will receive additional tools to help address their hearing loss and improve their care and overall quality of life. 🔄

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**Name has been changed to protect patient privacy.*

» Find sources for this article at leader.pubs.asha.org.

In addition to the higher association with physical disease that we found, other studies tie hearing loss to problems with mental health, cognitive functioning and activities of daily living.

Apply Now for a Mentored Teaching and Research Award

Students and faculty in communication sciences and disorders (CSD) have until April 15 to apply for either of ASHA's two mentored teaching and research awards—one for junior-level faculty seeking to advance their careers, and one for undergraduate and graduate students considering a PhD program and faculty-researcher career.

Awards from the Advancing Academic-Research Careers (AARC) and Students Preparing for Academic and Research Careers (SPARC) programs support self-identified mentored teaching and research activities designed to enhance academic career development.

Since the programs were launched 15 years ago, AARC has supported 114 faculty and SPARC has supported 175 students.

AARC

This \$5,000 award supports 18-month mentored teaching and research activities, such as incorporating new learning techniques to enhance teaching or collecting pilot data to strengthen a grant proposal.

AARC applications that focus on clinical practice research, implementation science, or interprofessional education or practice (IPE/IPP) are particularly encouraged.

The AARC award (on.asha.org/award-aarc) is part of ASHA's ongoing efforts to enhance faculty retention and address the PhD shortage. Program data for the 73 participants who received their awards more than three years ago show that 96 percent remain in academic positions and more than 80 percent have been promoted to the level of associate professor or above.



SPARC

The \$1,000 SPARC stipends (on.asha.org/sparc-award) support undergraduate and graduate students in 15-month mentored teaching and research activities. A faculty mentor guides the student awardee in achieving predetermined research and teaching tasks that expose the student to the work associated with a faculty-researcher career.

SPARC students can explore the work of a doctoral-level faculty-researcher, including teaching in CSD and delving into clinical research topics. Students in research-focused and teaching-focused programs can apply.

ASHA encourages faculty members to promote this award to

eligible students, who must fall into one of these categories:

- Junior or senior undergraduate enrolled in a CSD program.
- First-year master's degree student enrolled in a speech-language pathology program accredited by the Council on Academic Accreditation (CAA).
- First- or second-year AuD student enrolled in a CAA-accredited audiology program.
- Students accepted into a CAA-accredited graduate program for the 2018–2019 academic year.

For more information, email academicaaffairs@asha.org.