



Deafness is not a burden

NIH's David Rice learned to be an advocate for himself and others

David Rice wants to increase the Deaf and hard-of-hearing workforce at NIH.

Being deaf is not the same for everyone with the condition. Deafness means partial or complete loss of hearing in one or both ears and can range from mild to severe to profound. It can happen at any age and can be hereditary, genetic, or caused by environmental factors such as occupational noise. The ways in which people who are Deaf communicate also vary, and this affects how they move through the world or connect with other people.

For David Rice, being deaf meant not only learning to navigate a hearing world physically and socially but also discovering how to advocate for himself and others. As the Acting Branch Director for the Special Emphasis Program Branch at NIH's [Office of Equity, Diversity, and Inclusion](#), advocating for others is his job. He talked to NIH MedlinePlus Magazine about his experience and some things people may not realize about the Deaf community.

Deafness has a spectrum. Where do you fall within it?

I am severely deaf in both of my ears. However, I do have some hearing within my right ear; I can hear between 80 to 120 decibels in the right. In my left ear, I don't hear anything.

The hearing is not necessarily created equal, either. Pitches make a big difference—the higher the pitch, the less I hear. I can hear more clearly the lower tones and the lower pitch range. I do occasionally use a phone, and the majority of that is with people I know: my wife, my mom and my dad, my siblings. For the most part, I can hear them very well on the phone. I grew up with them; I know what their voices sound like.

But I rely heavily on American Sign Language (ASL) or lip reading. Lip reading is also not created equal in the Deaf and hard-of-hearing world. Although I may be able to lip-read fairly well, we can't assume that all Deaf people lip read. And lip reading is not perfect as some words have similar mouth movements but completely different meanings.

How did you learn to lip read?

In the late 1980s and early 1990s, closed captioning was not automatic like it is today. You had to buy a [closed caption decoder](#) box that sat on top of a television—the sound went into the box, and the box would produce the captioning.

Mister Rogers' Neighborhood was my favorite TV show of all time, and if you look, you realize most of the time the camera was on his face. I credit watching hours and hours of *Mister Rogers* with the captioning box with helping me develop lip-reading skills when I was very young.

With Zoom meetings today or on Microsoft Teams, if I know the individual very well, I generally can rely on lip reading to have the conversation. But if I don't know the individual well and I'm not familiar with their voice, I like to have the interpreter there to make sure I don't miss anything and that I get the full conversation.

But lip reading is not 100% accurate. There's a lot of filtering that goes on in my head, and I use context clues to decipher what a person is saying.

How did you learn ASL?

I had a sign language interpreter with me from kindergarten all the way through 12th grade. I was the only Deaf person in the school. I had no one to communicate with in ASL. So I did not know the language the way I know it now—I consider myself fully fluent in ASL now. But I used the interpreter in grades K–12 really to be a lip reader for me. At that time, I did what they called Signing Exact English, which uses typical English sentence structure. The sentence structure is different in ASL. In my junior or senior year of high school, I took ASL as a second language credit. It was “Zoom” before Zoom, with video classes through the University of Cincinnati.



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Then when I went to college at the Catholic University of America in Washington, DC, they had a level in the dorm building for students who were communicating in ASL. I got to stay there, and that helped me learn the language. I took more classes in it. But the pivotal moment was, when I could no longer play baseball in college, I found a coaching job [at the Model Secondary School for the Deaf]. I did that for eight or nine years, and that is how I learned to speak ASL fluently—being able to interact with the students every day and being involved in the community. I volunteered with the [Deaf in Government](#) nonprofit, and that helped me advance my skills more than in a classroom setting.



American Sign Language (ASL)

- Developed in the 1800s; shares elements of French Sign Language and local sign languages
- Uses fingerspelling of words as well as facial movements
- Complete, natural language
- Unique grammar, pronunciation, and sentence structure separate from English



SEE

Signing Exact English (SEE)

- Developed in the 1970s; 1:1 visual representation of spoken English
- Uses fingerspelling of words
- Not a language
- Follows English sentence structure; uses some ASL as well as unique signs

SOURCE: NATIONAL INSTITUTE ON DEAFNESS AND OTHER COMMUNICATION DISORDERS; AMERICAN ANNALS OF THE DEAF

How do you prefer to communicate with new people who may not know you're deaf?

It depends on the setting. If I'm meeting a hearing person, like at the store or giving a speech, generally I use my voice. I golf a lot, so if I don't know the people I'm golfing with, I say "Hey, I'm deaf. If you think I'm ignoring you, I'm not. I just didn't hear what you said." I've gotten a lot more comfortable doing that.

If I'm meeting a Deaf or hard-of-hearing person, I'll go straight into ASL. In the Deaf community, it's very easy to identify who's Deaf or those who are part of the Deaf culture. This includes interpreters or children of Deaf adults.

In a mixed group of hearing and non-hearing people, I prefer to speak because my verbal language is really my first language. I prefer to have an interpreter sign for me than for me to try to speak and sign at the same time. Interpreters are really skilled at this—my wife used to be an interpreter, and she's really skilled at speaking and signing at the same time.

Can you explain the concept of "language deprivation" and how that affects Deaf children's communication?

Language deprivation is denying [language] access from any individual. There's a critical period of time in the development of a child—from the day that they're born to a certain age—where language sets the foundation going forward. A lot of Deaf and hard-of-hearing children miss that window. And a lot of that has to do with the fact that some people don't think ASL should be part of the language development of a child who is Deaf and hard of hearing.

The Deaf community believes that spoken language and ASL should work together to help a child develop their language and comprehension skills. If you just focus on spoken language, they're going to fall behind. We need to study this more than what's currently out there.

FAST FACT: "Severe" hearing loss is the ability to only hear sounds once they are at least **71 to 90 decibels** (for example, a vacuum cleaner or alarm clock). "Profound" hearing loss is the ability to only hear sounds **at least 91 decibels** (such as a subway, passing motorcycle, or gas lawnmower).

SOURCE: [AMERICAN SPEECH-LANGUAGE-HEARING ASSOCIATION](http://www.aslha.org)



David Rice gives the opening remarks during the NIH 2018 National Disability Employment Awareness Month kick-off event.

What are some things you have to do in daily life that a hearing person maybe would not?

Right now, I'm wearing headphones so I can hear through those, but I don't hear anything else around me. It's very directional. There could be danger behind us, and I would not know. I have to rely on my vision a lot more. I take my hearing aid out to go to sleep, so I use a vibrating alarm on my phone to wake me up.

When I make phone calls to people I don't know, I use a video phone. I call and use my own voice, but an interpreter is there to sign what the person says. I have to get on an app, wait for an interpreter to come on, and then dial the number, so there

are extra steps. Another example is I have to set my own vibrating alarm for when the stove goes off.

On mass transportation, such as in an airport or on the subway, if they make an announcement over the loudspeaker, I will not hear that. I have to watch the reactions of other people around me. I don't go to movie theaters anymore because it's hard to find screenings with open captioning. The physical captioning screens some theaters have are too cumbersome to use.

Also, with podcasts today, everyone can learn things or read books just by passively listening. I have to download and read the transcript. I have to make time to sit down and read it, so I don't follow podcasts as much as, say, my coworkers do.

What brought you to NIH?

In high school, I entered the Presidential Classroom summer program run by Georgetown University. We went to NIH, and the Director at the time gave a speech to all the interns. Walking through those hallways as a 17-year-old, I thought, "This is where I want to be." At the time, I wanted to be a physician of some sort.

In college, I struggled with several of the science classes because the interpreters were not qualified for those classes. I wasn't understanding what the professors were saying, and trying to read from the book can be pretty difficult if you don't have someone to teach you what's going on. In retrospect, I had the right to say the interpreter was not an effective accommodation, and the university should have found an effective one.

I changed [majors] and got a psychology degree. I started coaching, and I formed more relationships with Deaf people. They empowered me, and I made a decision that if I ever got the opportunity, I'd make sure what happened to me does not happen to another 18-year-old.

When I got into college, I didn't know how to be an advocate for myself because when I was in high school, my parents were advocating for me. There's a big shift there.

I now know, as a 36-year-old man, that if I were more forward about my rights and for what I deserve, it probably would have been different. But I don't live with regrets.

While in college, I enrolled in the Department of Labor's Workforce Recruitment Program, which prescreens you for federal jobs. Two months later I got a call from NIH.

Can you talk about your work in the Office of Equity, Diversity, and Inclusion?

I was a management analyst at the National Eye Institute and later at the National Institute on Deafness and Other Communication Disorders. I then came to the Office of Equity, Diversity, and Inclusion five years ago and was the principal strategist for the People with Disabilities portfolio. Now as Acting Branch Director of the Special Emphasis portfolio, I oversee the People with Disabilities portfolio, among others, for underserved groups, including women, Black and African American, Native American, Asian American, Native Hawaiian, Pacific Islander, and Hispanic and Latino employees, and employees from sexual and gender minorities.

I want to make sure that people coming through the medical field feel empowered to ask for what they deserve. I want to increase the number of full-time Deaf and hard-of-hearing employees at NIH and have more Deaf and hard-of-hearing people contribute to the NIH mission.

Speaking of which, you helped reword NIH's mission statement. What's the story behind that?

My original intent when I spoke up [to NIH leadership] was to remove "disabilities" in general from the statement, but it was negotiated to remove "burdens." Language is powerful. "Burden" implies that a person's disability is a burden to either society or on ourselves. Most people with disabilities don't feel that their disability is a burden to anyone. Our disability brings a unique perspective and diversity to the world.

Previous NIH mission statement

NIH's mission is to seek fundamental knowledge about the nature and behavior of living systems and the application of that knowledge to enhance health, lengthen life, and reduce the burdens of illness and disability.

Current NIH mission statement

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When you write that mission statement, you're taking an ableist mindset that a person with disabilities is less than. So you're saying [a quarter](#) of the United States' population is less than. I took offense to that. I brought it up, negotiated, many of us agreed. It wasn't a full win, but I am on a subgroup of the NIH Advisory Committee to the Directors. We made [recommendations](#) to the larger committee to support people with disabilities and their perspectives.

What effect do you think the Food and Drug Administration's rule change for over-the-counter hearing aids will have for people who are deaf and hard of hearing?

Getting hearing aids over the counter at a CVS [without needing a prescription], for example, could be a game changer—especially for older people who are losing their hearing due to age. I think it's tremendously powerful to have that ability.

For me, my parents could not afford a hearing aid [when I was a child]. So while I still recommend going to the doctor and getting your hearing checked or fitted for a hearing aid, that's still not a reality for a lot of people. Who knows... if this rule was in place when I was younger, maybe I would have had access to hearing aids then? ■

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David Rice coached at the Model Secondary School for the Deaf in Washington, DC, for nearly eight years.