



“The Beginning of wisdom is the definition of terms.” -- Socrates

Understanding the Terms—Culturally and Audiologically

By Barbara Kelley

We get questions about how to describe people who have hearing loss and what are the appropriate terms. Journalists have become sensitive to writing about people with disabilities; however, we still see confusion in mainstream publications and inaccuracies in how hearing loss is described. We receive letters from members disheartened to see yet another writer confused about when you call someone deaf and when you call someone hard of hearing. Our editor explains the terms, how they’ve evolved, and how HLAA uses them.

There are 48 million people in the United States who have hearing loss. No matter what people choose to call themselves or how they identify themselves, it’s a matter of personal choice. Sometimes the labels are cultural, sometimes they are audiological. Here is an explanation of how terms have evolved over time and HLAA’s role.

People with Hearing Loss—A Brief History

At the Hearing Loss Association of America (HLAA) we say **people with hearing loss**. When there needs to be a more specific and identifying term, we break that down to **people who are hard of hearing**, and **people who are deaf (or Deaf)**.

HLAA believes that no matter what the label or how people identify themselves, they should make their own decisions about how they want to communicate and whether or not they use technology to use their residual hearing. There is no right way or wrong way to deal with hearing loss as it is intensely personal.

HLAA members tend to be people who use their residual hearing with amplification. They use all available technology—hearing aids, cochlear implants, personal listening devices, hearing loops, Bluetooth applications,

telecoils, infrared and FM systems, captioning on TV, Internet and captioned phones, and speechreading. Some people complement their lineup of coping and communication strategies with sign language, although sign language usually isn't their primary mode of communication.

HLAA believes in educating people about what is available and then people can make their informed choices about how to live with hearing loss.

Putting People First

When we write about someone with a disability, the person is paramount, then the disability. Here are some general rules that journalists follow:

- The umbrella term for all people who have hearing loss is **people with hearing loss**.
- We don't say **the hearing impaired, the deaf (or the Deaf), or the hard of hearing**.
- Use **people with hearing loss**; or **people who are deaf**; or **people who are hard of hearing**.
- **"People"** is the optimum word. Similarly, use **people with disabilities**, or **people who are disabled**. Don't categorize the individual by his or her disability. For example, don't say, "She is a Down syndrome baby," Say, "She is a baby who has Down syndrome."

Similarly, we also avoid sensationalizing hearing loss and giving it a negative label. We avoid saying things like "suffered with hearing loss," afflicted with hearing loss", "a victim of hearing loss.," etc.

"Hearing-Impaired"

The term hearing impaired was at one time preferred, largely because it took into account all people with hearing loss, both deaf and hard of hearing people. It was considered the umbrella term. It remains a clinical term used by hearing health care providers to describe a reduced level of hearing that is audiologically described as mild, moderate, severe, or profound.

However, over the past several years, some people have viewed the term as pejorative in that nothing is impaired and no one needs to be fixed. This thinking is most prevalent in the Deaf community who see their hearing loss as part of their culture and identity. To some people, the term focuses on what people can't do or that people are damaged. Yet, to others, they feel it is the best way to describe themselves when trying to explain their hearing loss. Again, it is a personal choice. In HLAA publications, we use **people with hearing loss**.

"Deaf"

Of the 48 million people with hearing loss, about two million are deaf and

use sign language as their primary mode of communication. Some consider themselves part of Deaf culture and *sometimes*, not always, resist any kind of surgical or technological intervention. That is why the uppercase "D" is used; i.e., to identify people as being part of Deaf culture who use sign language and typically go to schools for children who are deaf. The level of hearing loss can vary but it's usually a moderate-to-profound hearing loss. Some people who consider themselves deaf, might not have a profound hearing loss.

"Hard of Hearing"

Of the 48 million people with hearing loss, 46 million have all levels of hearing loss, including profound. They don't identify themselves as being Deaf. They use their residual hearing, hearing aids, cochlear implants and other hearing assistive technology noted above, and remain in the hearing world.

Some people might have a profound hearing loss but from a lifestyle and philosophical point of view would not call themselves deaf. For example, if someone loses her hearing later in life, she is less likely to learn sign language and unlikely to immerse herself in Deaf culture.

Why? The reason is usually because no one she knows uses sign language and she wants to remain in the hearing world and use everything available to live and work successfully with hearing loss while maximizing any residual hearing.

1979

In 1979, Rocky Stone, a former CIA agent who wore a powerful body aid, retired from the Agency and founded Self Help for Hard of Hearing People (SHHH). He did it because he had a profound hearing loss, had a successful career, and functioned in the hearing world by reading lips and using amplification. He didn't know sign language, and after he retired, he wanted to help others who didn't hear well.

He went in search of someplace to volunteer but found no organizations that focused specifically on people who considered themselves not deaf and not fully hearing; but, rather, **hard of hearing**. All the services, organized groups and any literature that was available focused on people who were deaf and mostly used sign language. There was nothing for people who were hard of hearing and wanted to use technology and stay in the hearing world, so he decided to start a new organization called SHHH.

Because of Rocky and SHHH members, the term **hard of hearing** was inserted into the lexicon for the first time on a national level. The term **hard of hearing** at the time was critical to creating awareness about millions of people who needed communication access other than a sign language

interpreter. For the first time, academic and consumer literature addressed what it was like to be hard of hearing.

One result of this new awareness was the Americans with Disabilities Act of 1990 (ADA) where communication access guidelines in public places was created both for people who are deaf and for those who are hard of hearing. The law requires "reasonable accommodation" and that can mean different things depending on the person and the situation. It provides for technology options in addition to sign language interpreters.

Rocky Stone was appointed by President Reagan to the Access Board who wrote the regulations for the ADA. If it weren't for Rocky Stone and SHHH members at the time who gave critical input, there would be nothing in the law other than sign language and captioning.

Today

SHHH is now known as the Hearing Loss Association of America. The name was changed in 2006 to reflect the growing population in the United States of people with hearing loss. The name has changed but the goal remains to create awareness about hearing loss prevention, early detection and treatment, and reduce the stigma associated with hearing loss. The mission to open the world of communication to people with hearing loss by providing information, education, support and advocacy has been unwavering.

HLAA continues to work at the national level for legislation and policies to ensure people with hearing loss live in a hearing friendly world. HLAA Chapters and State Organizations do similar work in communities across the county and provide peer support and hands-on opportunities to learn about hearing assistive technology.

For 35 years, no matter how people with hearing loss have been described, or what we call our organization, the Hearing Loss Association of America is the premier consumer organization for people with hearing loss, their families, friends and health care professionals who treat them. And as in the original name of the organization, **self help** is key. We give you information so you can make the choices right for you, and, in turn, help others do the same.

Barbara Kelley is deputy executive director of HLAA and editor-in-chief of Hearing Loss Magazine. She can be reached at bkelly@hearingloss.org.