

HEALTH

Understanding Deafness: Not Everyone Wants to Be 'Fixed'

Hearing people often assume that Deaf people would naturally want to take advantage of any method that could lead them to the hearing world. In reality, that assumption is far from true.

ALLEGRA RINGO AUGUST 9, 2013



Sergio Colas uses sign language while having lunch with Deaf friends in Pamplona, northern Spain, July 6, 2016. (SUSANA VERA / REUTERS)

When the police showed up, there were maybe 50 protesters, most of them Deaf, outside the Omni Hotel in downtown Los Angeles. Officers stepped out of their squad cars — four in total — and spoke to the protesters through an American Sign Language interpreter. They soon left amicably, though, apparently having not found much that needed policing.

The protesters were rallying against the Listening and Spoken Language Symposium, an annual event put on by the Alexander Graham Bell Association for the Deaf and Hard of Hearing (AGB). The symposium featured speakers,

workshops, and product displays centered around the topic of, as you may have guessed, listening and spoken language. Many of the sponsors and exhibitors were affiliated with companies that sell cochlear implants, surgically implanted devices that allow a Deaf or hard-of-hearing person to hear (to varying degrees).

The protesters were angry, but acting peacefully. The majority of them were Deaf. (Yes, with a capital D. In the book *America: Voices from a Culture*, Carol Padden and Tom Humphries explain, “We use the lowercase deaf when referring to the audiological condition of not hearing, and the uppercase Deaf when referring to a particular group of deaf people who share a language – American Sign Language (ASL) – and a culture.”)

The AGB has a complicated history with members of Deaf culture. AGB’s stated mission is to “[help] families, health care providers and education professionals understand childhood hearing loss and the importance of early diagnosis and intervention.” Their preferred methods for doing so emphasize spoken language, and de-emphasize the use of ASL. In practice, this translates to teaching communication methods like lip reading, learning to speak (by imitating breathing patterns and mouth shapes) and, relatively recently, using cochlear implant technology.

AGB’s reasons for their oral focus depends who you ask. When reached for comment, Susan Boswell, director of communications and marketing for AGB, told me that AGB “supports the development of spoken language through evidence-based practices focusing on the use of audition and appropriate technologies.” When I asked Ruthie Jordan, a Deaf activist who runs Audism Free America and helped organize the rally against AGB, she told me the reason is much more bottom-line. (I spoke with Ruthie and other Deaf people at the rally through my interpreter, Drew Tolson, who was extremely helpful.)

Ruthie’s take is that AGB “[Makes] money...by miseducating the parents of Deaf children.” Like many others at the rally, Ruthie feels that AGB takes advantage of the fact that hearing parents may not understand how a Deaf child can lead a functional, fulfilling life. A hearing parent in this situation may be easily convinced that a cochlear implant and an oral-based approach is the only legitimate option.

AGB’s “listening and spoken language” — based approach comes out of the school of oralism, which aims to educate Deaf children through the use of oral speech and lip reading (as opposed to manualism, which advocates for the primary use of ASL

in Deaf education). The goals of oralism may not sound controversial to most hearing people, but oralism has a long and problematic history.

In the 1860s, Alexander Graham Bell was a prominent oralist, and to some, an important figure in the spreading of audism — the belief that it is inherently better to be able to speak and hear. Although he surely thought otherwise, Bell had an ugly relationship with the Deaf community. Though his mother and wife were Deaf, he was intent on wiping out “hereditary deafness.” He removed Deaf faculty from schools, demanded the same schools stop their use of ASL, and advocated against “deaf intermarriage.”

Bell was also involved in the Eugenics movement, serving for a time as chairman of the board of scientific advisers to the Eugenics Record Office.

In 1880, prompted by talks between Bell and other prominent figures in deaf education, 164 delegates met for the Second International Congress on Education of the Deaf. Only one of the delegates was deaf. At the conference, a resolution was passed that banned sign language in schools, in an effort to encourage spoken language skills, and thus “[restore] the deaf-mute to society.” Other passages in the resolution urge us to “[consider] the incontestable superiority of speech over signs,” and argue that teaching deaf people to speak English will “[give them] a more perfect knowledge of language.” After its passage, schools in Europe and the United States ceased all use of sign language.

Given this history, some Deaf people feel that oralism is rooted in audism. Some argue that the sentiment of needing to “restore [Deaf people] to society” still underlies the AGB and companies affiliated with them. In fact, many Deaf people and Deaf allies, like the ones at the rally, strongly oppose the AGB and their affiliates. These people argue that the AGB and its affiliates propagate practices that harm Deaf people, all for the sake of making money. And indeed, AGB has a financial stake in the sales of cochlear implants as well as other “hearing technology.”

In addition to running an academy that trains teachers in oral-based educational methods, AGB “provides advertising opportunities to companies seeking to promote their products to individuals who are deaf and hard of hearing.” According to AGB’s website, one of their “partners in hearing” is Med-El, a large manufacturer of cochlear implants. As I mentioned earlier, the exhibitors and sponsors for their

2013 symposium include a long list of companies who sell or otherwise advocate for cochlear implant technology: Advanced Bionics, Cochlear America, the American Cochlear Implant Alliance, and many others.

Those who oppose the AGB's practices argue that this is a large coalition of companies that stand to benefit from the sale of cochlear implants. This, they argue, is a conflict of interest, and renders any information distributed by these companies untrustworthy. Ruthie Jordan told me she feels that AGB is "miseducating the parents of Deaf children...[AGB is] earning their millions by perpetuating misinformation. They are using the ears and the bodies of Deaf people to make themselves rich." She thinks AGB's actions are "only related to spoken language and 'fixing' Deaf people ... they see Deaf people as sick, disabled, as having a deficit."

Many within Deaf culture feel similarly. They argue that the AGB harms Deaf communities by propagating large amounts of information about oralist methods — including cochlear implants — and treating ASL as "less than" spoken English.

The controversy is sometimes difficult for hearing people to understand. Hearing people often assume that Deaf people would naturally want to take advantage of any method that could lead them to become part of the hearing world — especially cochlear implants, the most advanced hearing technology we have. In reality, that assumption is far from true. To members of Deaf culture, American Sign Language is a cultural cornerstone. Because Deaf children who receive cochlear implants at a young age will likely be educated in the oralist method, they are less likely to learn ASL during their early years, which are the most critical years of language acquisition. For some Deaf parents, that would result in a child who speaks a different language than they do. Understandably, some see this as a loss of culture—one that, in some cases, has been passed down through generations. What may seem to a hearing person like an opportunity may be seen by some Deaf people as a loss.

The debate stems from a fundamental disagreement: one group sees deafness as a disability, and the other group sees it as a culture. The trouble is that the former group holds a disproportionate amount of power, and the latter group are the ones affected.

Jeff DuPree volunteers with Audism Free America, and is a proud sixth-generation Deaf person. I spoke with him through an interpreter at the symposium. Jeff told

me, “My whole life I’ve lived as a Deaf person. I married a Deaf person, I’ve worked and associated with Deaf people, and I’ve had no problem in this world. So why are organizations like this trying to take away my right to live the way I want to live, my right to raise my children the way I feel they should be raised?”

It’s not an easy question to answer. For their part, AGB maintains that they are simply advocates for the Deaf and hard of hearing. They point to the many people who, they argue, they have helped, by giving them information, grants, or general guidance related to cochlear implants and overall oral-focused education. AGB’s website states that they “[Help] to ensure that every child and adult with hearing loss has the opportunity to listen, talk and thrive in mainstream society.”

That’s not a disingenuous statement. The question is whether the affected people are receiving the full truth about “mainstream society.”

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