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### Access: Multiple Avenues For Deaf People

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**Authors**

D. DeLuca, I. W. Leigh, K. A. Lindgren, and Donna Jo Napoli

## Introduction

DOREEN DeLUCA, IRENE W. LEIGH,  
KRISTIN A. LINDGREN, AND DONNA JO NAPOLI

The past half-century has seen major developments and attitude shifts—at the technological, institutional, societal, and personal levels—that have improved the lives of deaf, hard of hearing, and Deaf people. Nevertheless, there remain hurdles for deaf people to jump if they are to have full access to the rights and privileges enjoyed by the larger hearing society. And there remain hurdles for hearing people to jump if they are to respond to the need for equal access of all members of society. The essays in *Access: Multiple Avenues for Deaf People* address some of the practical and theoretical issues and advances in three major areas of access: assistive technologies, education, and civil rights.

Many of the essays and interviews in this volume grew out of the Signs and Voices conference, a four-day event in November 2004, which took place at Swarthmore, Haverford, and Bryn Mawr colleges. That conference was holistic, looking at multiple aspects of d/Deaf life, not just questions of access, and, accordingly, many works from that conference appear in a sister volume to the present one: *Signs and Voices: Deaf Culture, Identity, Language, and Arts*.<sup>1</sup> Other essays were written specifically for this volume at the invitation of the editors.

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1. Following a convention first established by James Woodward, we use “deaf” to refer to individuals who are audiologically deaf and “Deaf” to refer to those who use sign as their primary language and identify with Deaf culture. Because these categories are overlapping and not always easy to tease apart, we also adopt the more recent practice of using “d/Deaf” to represent deaf and culturally Deaf people.

Taken together, the essays in *Access: Multiple Avenues for Deaf People* outline what is presently available and effective and what is still lacking or ineffective in the area of access. They give both personal and professional viewpoints, with an eye toward informing the reader regarding choices that must be made on the individual level as well as on the societal level. We hope that the volume will prove useful to scholars and teachers in a variety of fields, to their students, and, especially, to general readers, both d/Deaf and hearing, who are seeking information about access.

## ASSISTIVE TECHNOLOGIES

Part One opens with Maggie Casteel's "Building New Ramps with Hearing Assistive Technology." The current explosion in communications technology provides increasing numbers of, and better quality access to, accommodations for deaf and hard of hearing people. Ms. Casteel points out that, to set the stage for assistive technology to be most effective, we must develop awareness on the part of society in general, and of families and employers in particular, of the communication needs of deaf and hard of hearing people. She has advice for hearing people dealing both with deaf and hard of hearing people who choose to be oral and deaf and hard of hearing people who choose to sign. She describes hearing assistive technology (HAT) that can improve awareness and accessibility to acoustic signals—from devices that convert sound into something else (light or vibration or text or sign language images), to those that enhance sound (including assistive listening systems such as FM, infrared, and induction loop, as well as personal listening systems, which may help with TV, radio, and stereo). She outlines the rights of deaf and hard of hearing people with regard to "reasonable accommodation" protected by the law and lists situations under which safety is threatened without HAT. Ms. Casteel goes step by step through each device so that the reader can be truly informed.

In the next chapter, Al Sonnenstrahl has a conversation with the editors about all aspects of telecommunications. Mr. Sonnenstrahl began his career in advocacy by convincing the U.S. Civil Service Commission to change their hiring rules and allow deaf engineers. After ten years as an engineer, he moved on to advocate for equal access for deaf people in multiple ways. He persuaded AT&T to provide operator services and directory assistance to deaf people. As the director of

Telecommunications for the Deaf, Inc., he worked with others to make sure that the draft of the Americans with Disabilities Act (ADA) addressed the needs of deaf people before it was passed. He gives details on the history of the development of communication devices and services, including video relay service and voice carry over, provides information about the choices available in visual communication services versus text and voice services over the phone line, and discusses the role of various agencies in ensuring access for deaf people. He stresses the need to maintain the text format in telecommunications and warns that we must not lose closed captioning as TVs turn digital. Further, he says, we must monitor developments to maintain interoperability and interconnectivity of different devices and systems, so they work together in tandem—Blackberry pagers communicating with Sidekick pagers and so on. And we must ensure that deaf people have access to 911 centers, not just through landlines, but with wireless systems and the Internet, where now, unfortunately, emergency centers are unable to identify caller locations.

In the final chapter in this section, “Cochlear Implants,” the Alfred I. duPont Hospital for Children team of Robert C. O’Reilly, M.D., Amanda Mangiardi, rehabilitation therapist, and H. Timothy Bunnell, psychologist, offer a detailed description of how cochlear implants work and take us through every step of the process of receiving one—from determining whether someone is a suitable candidate, to the surgical process itself, to rehabilitation therapy following implantation. First, they describe auditory anatomy and physiology and explain how hearing occurs under ordinary circumstances. Next, they detail how cochlear implants deliver auditory information to the brain and give a complete picture of cochlear implant surgery. Determinations about the advisability of implantation are made by a team of professionals who educate and counsel parents as well. The source and severity of hearing loss, the amount of time between the onset of deafness and potential implantation, and the commitment of the child and family to rehabilitation therapy after implantation are factors that determine whether a child has a good chance of benefiting from implantation. For successful rehabilitation therapy, which works on both the perception and production of particular language sounds, parent participation is essential. Other factors that correlate with success are the child’s non-verbal IQ and the quality of the implant device. And the best multi-channel implants using the latest speech processing algorithms support better spoken language development. The article ends with a summary

of the types of school environments typically offered to the child with an implant and comparative studies of their success.

## EDUCATION AND LITERACY

The essays in Part Two explore approaches to educating deaf children, offering both research-based analyses and accounts of personal experience. In the first essay, "Civil Rights Issues in Deaf Education," Jami N. Fisher and Philip J. Mattiacci give a history of the legal acts which have aimed to ban discrimination against persons with disabilities and point out the need for legal recognition of the discrimination that d/Deaf individuals experience. In particular, they zoom in on the needs of culturally Deaf people as a linguistic minority within the educational setting. The mainstreaming of Deaf children has had disastrous effects for many children. In contrast, Deaf children educated in an environment which facilitates visual access that appropriately meets their linguistic needs have a better chance to achieve academically. The authors support this argument with a brief outline of the history of Deaf Americans from the early 1800s on. If Deaf children are viewed not in audiological terms, but in cultural terms, their needs can be recognized and, accordingly, met. Mixing Deaf children of various ages and cognitive skills in a classroom simply because of their English ability (a commonplace practice in mainstreaming programs) leads to social and emotional problems. Additionally, there is a crying need for teachers trained in American Sign Language (ASL) who are knowledgeable about the educational needs of Deaf children; for adequate support and training of parents of Deaf children, including early intervention programs; and for adult Deaf role models from whom Deaf children can learn cultural and linguistic awareness. Finally, Deaf children need access to extra-curricular activities. The authors end with a list of recommendations for anyone involved in the education of Deaf children.

In "Inclusion and the Development of Deaf Identity," Michael Stinson discusses the choices available for d/Deaf children in their local public schools. He distinguishes between placing the child in a regular classroom and asking that the child adapt or be taken out of the regular classroom (mainstreaming), and placing the child in a classroom that adapts to the needs of that child (inclusion). In many mainstreaming environments, the child winds up in a special classroom for much of the day, with interpreters and other supports. Inclusion, therefore, theoretically has a better chance of welcoming the child, but only

if teachers and students sincerely view the deaf child as a genuine member and, thus, use both ASL and English in an appropriate balance. Further, there needs to be a sufficient number of deaf children to make social interaction with deaf peers possible, interaction which is important for the development of a healthy identity. Additionally, the classroom needs good communication support, such as interpreters, notetakers, speech-to-text services, etc. Stinson describes patterns of identity among deaf people, from those whose culture is hearing, to those uncomfortable in both Deaf and hearing environments, to those whose culture is Deaf, to those who are bicultural. Research shows that deaf youths and adults who are culturally Deaf or bicultural report the greatest satisfaction with life. Inclusion programs that isolate deaf children within a hearing environment rarely provide the opportunity for learning about Deaf culture and, thus, developing a healthy identity. Mainstreaming, on the other hand, tends to group deaf children together, allowing for some Deaf acculturation, but far from enough to ensure good self-esteem. Stinson recommends that all programs include opportunities for Deaf children to interact with Deaf adults and peers and promote extracurricular Deaf activities.

Lisa Herbert shares with us her experiences growing up in “Deaf, Signing, and Oral: A Journey.” She was born hearing into an Afro-Canadian family with Caribbean roots. At age four she became deaf as a result of meningitis. Within a year, it was clear hearing aids were not effective, so she was fitted with a cochlear implant. She had a variety of school environments, from being the only deaf child mainstreamed into all-hearing classes, to being in a school that had enough deaf children to put them in a discrete classroom. She made friends and once even represented her school at the regional spelling bee. When she had trouble speechreading, she learned to smile wide. The summer after ninth grade, she attended a camp where she learned ASL, loving how relaxed she could be in a visual environment. But then it was back to an oral environment, with class discussions that were too complex and fast to follow with speechreading and no interpreter. After eleventh grade, she headed off to Gallaudet University and faced the question of why she chose to have a cochlear implant. She wasn’t using it at Gallaudet, so she stopped wearing it. Still, she didn’t really fit in, so she transferred to the Rochester Institute of Technology. While there, her cochlear implant stopped functioning properly. It was old and only had a single channel anyway. Ms. Herbert describes the difficult decision she faced: whether to be re-implanted or not and facing all the

repercussions that would mean to her identity. At the age of twenty, she was re-implanted. She finished college, worked for a while, and then attended Gallaudet University's graduate program in school psychology. She now works at the Indiana School for the Deaf, where she feels completely comfortable as a signing Deaf person who continues to use her cochlear implant.

The editors' conversation with Grace Walker, focusing on her personal experiences with a cochlear implant, ends this section. Ms. Walker grew up in a Deaf family and attended a residential school for deaf people from kindergarten through high school. She used an FM system and a hearing aid as a young girl at school. When she was 40 years old, she got a cochlear implant. She was judged a good candidate for surgery because her expectation that the implant would enable her to hear environmental sounds but not necessarily to decipher speech was realistic. Her family and friends at Gallaudet University, where she was working, had mixed reactions to her decision, but generally supported it. After the surgery, she experienced nausea for two weeks. She persisted, though, working hard at speech therapy for a year. The cochlear implant did allow her access to environmental noises, but it did not help her with language. A few years later, the nausea returned so severely, she had to be hospitalized. And a couple of years later, she had another attack of vertigo, even worse than the earlier ones. She took off the external apparatus of the implant, but for a year she experienced mild vertigo almost all the time. After that, it came sporadically. Now, if she experiences the dizziness, she battles it with yoga and medication. She no longer uses her cochlear implant and has been vertigo-free for years. She does not regret getting the implant, despite the vertigo.

## CIVIL RIGHTS

Part Three consists of essays and conversations that address the civil rights of d/Deaf people in the workplace, in settings where they receive education about and treatment for HIV/AIDS, and in telecommunications. We begin with the editors' conversation with Christy Hennessey, focusing on rights in the workplace. Ms. Hennessey grew up with parents who were proactive in her education, relocating the whole family so that she could attend a school for deaf people and then working to change the school curriculum to better meet the needs of the children. Their advocacy work influenced her career choice: She now instructs



Deaf people on how to advocate for themselves. She teaches Deaf clients how to write a résumé and gives practice interviews for jobs. Once on the job, if people have problems, she helps assess what their needs and rights are, particularly with respect to the ADA. She urges them to inform employers that they are entitled to reasonable accommodations, including interpreters at staff meetings and other events as well as technology such as videophones. Sometimes employers benefit from the sensitivity training workshops that she runs. In most cases, once an employer understands what a deaf person needs in order to work effectively in a safe and friendly environment, the employer is cooperative. But if problems persist, Ms. Hennessey will advise an employee about how to file a complaint with the Equal Employment Opportunity Commission. Ms. Hennessey gives practical advice while adding a historical perspective to the issue of employment since the passage of the ADA. Her services are free, and similar services are available in many urban areas.

Our next editors' conversation is with Tony Saccente, focusing on HIV/AIDS counseling. Mr. Saccente worked for Housing Works, in New York City, which helps provide housing health care, job training, and other vital services to homeless people with HIV/AIDS. Mr. Saccente did Deaf outreach, particularly to the gay community. He describes a survey conducted in 2000 by the National Development and Research Institutes, Inc., which showed that the percentage of HIV-positive Deaf people in NYC, relative to the Deaf population of NYC as a whole, is three times that for hearing people. Part of Mr. Saccente's work was educating the Deaf public, since social factors and language barriers (in the case of immigrants) inhibit access to information. He trained interpreters to use frank language about sexual activities to avoid misunderstandings and to give explicit directions about what people should do if they are infected or think they might be infected. He trained peer education groups, so that his students, in turn, could go out into their communities and educate. While the Deaf community in NYC is close-knit, it has subgroups (e.g., Asian Americans, Latinos, African Americans, and gay Americans), and Mr. Saccente worked to find ways to communicate sexual, social, and medical information that was culturally acceptable to these subgroups. His workshops used visual aids and role-playing to deal with emotional matters such as anger management (people feel "why me?") as well as medical matters. One of his goals is to inform the public about testing options; people are more likely to wait for results if tests are reliable and quick—and

it is imperative that people know their own health status if they are to behave appropriately.

In “HIV/AIDS in the United States Deaf Community,” Leila Monaghan reviews recent studies of Deaf attitudes toward HIV/AIDS. Repeatedly, Deaf people display knowledge about AIDS-related maladies but seem to know little about how to practice safer sex to avoid transmission. This information gap is due, in part, to the difficulty Deaf people experience in reading medical material. But when medical material is presented in ASL, people understand readily. Deaf people want accessible information so they can protect themselves. Interactive group presentations, workshops, peer information networks, and straightforward, but culturally sensitive, presentations of information from outreach groups at d/Deaf events were particularly well received by the respondents. The interviews revealed hesitancy to seek information about HIV because of stigmas attached both to being gay and to being HIV-positive. Because Deaf communities are small, fear of lack of confidentiality is intense. Unfortunately, information on the extent of HIV/AIDS among deaf people is hard to come by, since most states do not collect information on the hearing status of people being tested for HIV. But the information we do have is unsettling: Deaf people are significantly more likely than hearing people to be HIV-positive, and in the youngest age groups, deaf people are over four times more likely to test positive—a difference that parallels the knowledge gap between deaf and hearing people. Deaf people feel clueless about where to go for testing. Even if they locate a testing site through the Internet, they do not know if ASL services are provided. Once a person is diagnosed HIV-positive, sometimes no further support is offered. AIDS in the Deaf community is epidemic, and information that can reduce risk is essential, particularly because health care is not easily accessed. Yet limited funding threatens the very programs that help the most.

We close this volume with “DPN and Civil Rights” by Gregory Hlibok, who grew up in a Deaf family passionately involved in advocacy. As a child, he protested whenever he met communication barriers. So as a student at Gallaudet University, it was natural for him to lead the Deaf President Now (DPN) movement that resulted in the selection of the university’s first Deaf president. Subsequently, student body governments across the country asked for his protest “tool kit.” But Mr. Hlibok couldn’t supply one; the protest succeeded because the students involved had grown up oppressed, and, according to him, that made them ready to fight more effectively for their rights than any

hearing person could have. With the DPN protest, Deaf people took control of their destiny, and hearing people became aware of their capabilities. In the years following the protest, demand for ASL courses increased, as did job opportunities for Deaf people. Mr. Hlibok testified in support of the ADA and then saw the passage of the TV Decoder Circuitry Act, and later, the Telecommunications Act. By 2001, he was working at the Federal Communications Commission as an attorney who advises in regulating telecommunication relay service matters and captioning. Laws requiring “functional equivalency” for Deaf and hearing people with respect to technologies must be interpreted as having moving goals, so that providers constantly ensure availability to the deaf consumer and improvements whenever new technology enables a higher level of functionality. Targeted laws often have unexpected benefits; closed captioning benefits anyone trying to learn to read English, not only Deaf people. Changes such as the instituting of closed captioning helped to raise awareness on the part of the hearing public of deaf people’s needs. We must applaud technological innovations, but stay vigilant in seeking and protecting equal opportunities and accessibility for all.

The essays in this final section highlight both the tremendous advances in protecting the civil rights of d/Deaf people and the work that remains to be done to educate everyone about d/Deaf and hard of hearing people’s rights and to ensure the ongoing protection of these rights.

