

Talking Culture: Deaf People and Disability Studies

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THE HISTORY OF DISABILITY STUDIES OVERLAPS nicely with the history of deaf studies. Both came into being roughly at the same time, in the last two decades. Just as there are new programs of disability studies in universities across the United States and around the world, there are new programs of deaf studies at places like the University of Iowa, Gallaudet University, Northeastern University, and California State University, Northridge. The idea of a "deaf studies" is still so new that the phrase feels novel and unexpected, but the idea gained a certain inevitability as a field of inquiry began to develop around the history of deaf people, their lives, their communities and cultures.

Truth be told, deaf people see themselves an odd fit in disability studies. We've been segregated for such a long time that we see our history as set apart from others, and

it feels strange to have the company of other disabled people. For most of America's history, deaf children have lived in institutions designed exclusively for them in nearly every state of the country. Some states had more than one institution: New York, for example, had as many as eight schools for deaf children through most of the twentieth century. By the late 1970s, these institutions began to decline as deaf children were moved into public schools with hearing children as part of a wider trend toward deinstitutionalization. Considering that the first school for deaf children in the United States was founded in 1817, we have little experience outside deaf schools and the segregated lives that developed around them. Without question, mainstreaming has had a huge effect on deaf people, but it is part of a much broader social change.

I intend with my brief overview of the recent history of deaf people to show how disability studies as a field will need to acknowledge that different disabilities have their own histories, each defined by unique trajectories. This might seem like a confusing cacophony of voices, but these different

charity caste, the broadcasts at the same time pictured people without disabilities as their opposites: physically healthy and whole, giving rather than receiving charity, socially valid.

And by having nondisabled presenters do almost all the talking, the charities reinforced the power of nondisabled people in general to define the social meaning of "disability" and the social identities of people with disabilities. Telethons empowered nondisabled emcees to explain to nondisabled viewers the daily experience of disability. "We hope to give you a little more understanding of what life is like for someone with a disability," announced a local Easter Seals host in 1990. But, admitted another in 1988, one of the frustrating things about hosting this show is that one is often asked "to describe what someone in a wheelchair is going through, and frankly we can only imagine what it is like." Yet, undaunted by their ignorance and authorized by the charities, the hosts talked on and on.

During the latter half of the twentieth century, growing numbers of Americans with disabilities resisted their relegation to social invalidity. They organized themselves into a movement—more accurately, an assemblage of movements—that challenged dominant views of disability. Instead of attributing disabled people's social and economic marginalization to pathology, their campaign adopted a minority-group perspective. More urgent than remedial measures to fix individuals was the instatement of equal access, reasonable accommodations, and antidiscrimination protections. Rejecting the charity approach that beseeched attention to disabled people's needs, the movement demanded civil rights enforcement to ensure their right of access to society.

This activism led in the 1980s and 1990s to criticism of and then protests against the telethons. Whereas those broadcasts assumed that "affliction" and "misfortune" were inevitably and self-evidently the state of being of anyone with a disability, disabled activists scorned those suppositions as not objective statements

of biological facts but social prejudices that justified discriminatory practices. The charities could not ignore the demonstrations or the emergent minority-group mentality that fueled them. In fact, some of the agitation came from activist constituents in the organizations themselves. And so, in various ways, the telethons sought to co-opt or criticize, address, assimilate, or adopt the activist perspective.

On and off the broadcasts, the controversy generated public debate that touched on, without deeply exploring, let alone resolving, a clutch of questions: Is disability inherent defectiveness, socially constructed devaluation, or human variation and difference? What are the real needs and interests of people with disabilities, and who is qualified to determine them? Could Americans with disabilities legitimately demand equal dignity and equal rights while insisting that society provide for their distinctive disability-related needs and alternative modes of functioning as a matter of right? Could disabled citizens assert their fundamental equality if they admitted that some conditions involve intrinsic limitation and suffering? Is it possible for charity publicists to promote amelioration of genuine human suffering without demeaning the people they ostensibly seek to help? Are American values about need, justice, equality, and difference compatible with one another or irreconcilably at odds?

Neither the critics of the telethons outside the disability rights movement nor the broadcasts' apologists examined the complexity or significance of these issues, ideologies, and messages. They didn't wonder why the infantilizing and sentimentalizing of disabled people had such appeal with the American public. They didn't seek to explain why and how these forms of mendicancy worked. They didn't ask if the telethons' solicitation techniques were, in fact, "the only way" to fund medical research and medical treatments and social services, as Bob Greene and others had learned to take for granted. They did not ponder what the telethon mode of fund-

histories offer a pathway to understanding both deaf studies and disability studies. I believe these new fields of inquiry can address what many deaf people see as some of the most pressing questions of our lives: what is the future of our bodies, and how will science and technology use us to address questions about the future?

The problem of voice. Among the first signs of change in deaf communities in the United States is the emergence of a changed language about ourselves, our language, and our culture. Over the last forty years, we have devised new vocabulary and new ways of talking about ourselves. My frequent collaborator and coauthor, Tom Humphries, describes this change as a transition from "culture talking" to "talking culture," borrowing from Jim Clifford's characterization of modern cultures (Clifford; Padden and Humphries). Deaf people have acquired not only a new vocabulary but also a new consciousness, indeed a self-consciousness about themselves and their behaviors.

In a 1913 film of the president of the National Association of the Deaf, George William Veditz, giving a signed oratory, we see examples of the voice of deaf people in the early part of the century. Titled "The Preservation of the Sign Language," Veditz's delivery is a fiery and impassioned defense of sign language in the face of attempts to banish it from schools across the country. As we read a letter Veditz wrote containing the English text of his signed speech, we see how he used the vocabulary of his time to refer to himself and his community as "deaf-mutes" using "the beautiful sign language." He warns of "a new race of pharaohs that knew not Joseph" who advocate the banishment of sign language from deaf schools, and he strikes out at the "oral Moloch that destroys the mind and soul of the deaf." Veditz's speech is a beautifully constructed example of the problem of voice that plagued deaf people at the time. Douglas Baynton explains in his history of the deaf

community in the nineteenth century that deaf people persisted in using religious and divine accounts of their language and their existence while their opposition was shifting to the language of rationality and science that shaped much of oratory at the close of the century. As impassioned as the protests on film were, deaf people were essentially silent and silenced—deemed to be without sound and comprehensible only to those few who knew sign language.

As they moved into the twentieth century, deaf people agreed to modernize their language, first ceasing to refer to one another as "deaf-mutes" and "deaf and dumb" in an effort to end the perception of themselves as silenced (Fay). Whereas once their language was simply, as Veditz called it, "the sign language," which conveyed "their thoughts and souls, their feelings, desires and needs" (Letter), deaf people now use "American Sign Language," capitalized and labeled for its country of origin, and they refer to their lives in terms of a deaf culture. The divine language has yielded to a changed perception of sign languages as one type in the array of natural human languages around the world. Sign languages have grammars, and these grammars vary. These new ways of talking about sign languages are part of a broader shift, moving deaf people toward the family of languages and cultures. This is what we mean by "talking culture."

To illustrate the recent history of deaf people, I focus on three aspects: the legacy of deaf schools; deaf people's transition from private, segregated lives to more public ones; and how deaf people exploit technology in a struggle for voice.

The legacy of deaf schools. Beginning in 1817, America embarked on a prolonged effort of building asylums and institutions specifically for deaf children, an impulse that continued until 1953, when the last school of this type was built in Riverside, California (Gannon). Hartford was the site of the first

asylum in 1817, followed by a school near New York City and another in Philadelphia by 1820. Ohio opened its state school in 1829, and South Carolina's appeared in 1849. New schools continued to open at a steady rate until the end of the century, when nearly every state had at least one. Many, though not all, of these schools had blind departments on the same campus. (The joint histories of blind and deaf children on these campuses are rarely described, but worthy of attention [Crockett and Dease; Bickley].)

Such faith was invested in these asylums and institutions that they came to dominate education of deaf children for nearly 150 years. Today, if you ask deaf men and women older than thirty where they are from, they will name the deaf school they attended—"Berkeley" refers to the original site of the California School for the Deaf (it has since relocated to Fremont). My father was born in Chicago, but he will say he is from Faribault, where he attended the Minnesota School for the Deaf his entire childhood. Built in the centralized and separate asylum architecture characteristic of the nineteenth century, deaf schools created a strong sense of delineation, separating deaf children from other children living outside the school. My colleague Ted Supalla remembers how a child from the neighborhood once pierced the iron walls surrounding Ted's school and rode a bicycle across campus, drawing incredulous stares from deaf students and teachers. Asylums were places of respite, apart and separate, and outsiders rarely came on campus.

The schools rearranged the geography of deaf communities in the United States. Whereas deaf communities of the American colonial period existed on a small scale throughout the country (Lane, Pillard, and French; Lane), by the nineteenth century these clusters were reorganized into larger communities with schools at their center. This geography continues to this day; there are robust deaf communities in Philadelphia, Wash-

ington, New York City, and Rochester, all of which had large deaf schools at their core.

Within the schools, deaf children were carefully grouped. They were always taught separately from blind children. Some deaf schools segregated children by gender as well. By the mid-nineteenth century, racial segregation was instituted in deaf schools throughout the South. In Tennessee, Virginia, South Carolina, and Arkansas, black deaf children attended school in separate buildings. In Louisiana, West Virginia, Maryland, and Florida, they attended separate campuses, sometimes in different parts of the state (Hairston and Smith; Padden and Humphries; Joyner; Bickley).

This is a complicated legacy, both alienating and comforting. Deafness is an uncommon condition. Often deaf children are alone in early childhood, without siblings or parents who are deaf. What asylums and institutions provided for deaf children through the nineteenth century was a chance to be with other deaf people. As the schools sought out deaf children and brought them under the protective care of the institution, deaf children met others like themselves. In his account of asylums, Michel Foucault describes the coming together of inmates as creating in one another "recognition by mirror," a realization that one's insanity is not so unusual (152). The effect of this realization deflates the inmate's sense of uniqueness, leading eventually to demoralization and then oppression by the caretaker. For deaf people, the flip side of recognition by mirror is the possibility of elation—not deflation—at being surrounded for the first time in their lives by real-life versions of the self, in deaf teachers and fellow deaf students.

On the one hand, deaf schools are places of overbearing management of children's bodies, which, sadly, leads often to physical and sexual abuse. At the same time, these are places where deaf children meet others like themselves. Children who do not learn sign

language at home can acquire it at school. Today, facing a changed sentiment about institutions, many of these schools closed doors and no longer operate. Others have redesigned their buildings to seem more like smaller-scale private schools and not as massively institutional as they were in the nineteenth and twentieth centuries. Maryland School for the Deaf tore down its large Old Main Hall and replaced it with a more modest brick building. When Pennsylvania School for the Deaf faced a decline in enrollment, it sold its rambling grassy campus in the Germantown section of the city and moved to a smaller location, a former boys' military academy. Modern deaf schools are more likely to be regional schools than state schools, downscaling their ambition and drawing their population of deaf children from urban areas like the Bay Area, the Washington metropolitan area, New York City, and Riverside, California. Far fewer children board at such schools today, now known in deaf education by the more suitable term "special schools."

The transition from private to public. Though deaf theater has been a mainstay of the community since its earliest history, the first professional national deaf theater was founded less than forty years ago, in 1967. Funded with a federal grant and headed by a hearing artistic director who had worked in Broadway theater, the National Theatre of the Deaf brought together deaf actors who were popular performers in deaf clubs. These were small social clubs found in cities and towns throughout the United States. New York City had twelve such clubs in its boroughs, catering to those who played sports or poker. At least as many existed in Ohio, where deaf men and women were employed in the defense industries during the First and Second World Wars. Deaf clubs were nearly always made up of deaf patrons (except for hearing spouses and children), and their activities were separate and private. Signed performances on deaf club stages were often not voice-interpreted.

Much like Yiddish theater of the 1930s and 1940s, deaf club theater was presented for deaf people by deaf actors and deaf directors. They staged vaudevillian skits, beauty pageants, and sign translations of popular plays, pleasing their loyal club patrons.

When the first professional theater company was established, the actors began with translated performances of poetry by Elizabeth Barrett Browning and plays by Dylan Thomas. A few years later, they mounted an original production called *My Third Eye*, in which they told vignettes about being deaf, including a segment on sign language. This was arguably their first performance in public featuring an original piece intended for an audience who knew neither sign language or deafness. I have written elsewhere that this was a pivotal moment in the history of the community, when deaf poets and actors began to imagine how to present themselves, their language, and their practices to others (Padden and Humphries). At about the same time, not coincidentally, the name for their language changed first to "the American sign language" and a few years later to the fully capitalized "American Sign Language" as they acquired a new vocabulary for describing the elements of the language.

Technologies of voice. As they began to tour the country performing their brand of sign language theater, the deaf actors were accompanied onstage by hearing actors, who spoke the lines simultaneously in English. Whereas in deaf clubs the deaf actors performed alone and silently in their language, on a public stage they shared the spotlight. The intent was to give voice to performance that was formerly intelligible only privately, but interaction transformed the performance. As the deaf actors performed alongside the spoken word, they found that their signing could be too slow or too fast for the spoken translation. The signing had to be coordinated with speaking, and in the process, the actors lost full control of the stage.

Their signing changed its tempo, increasing in rhythm from the comfortable pacing of the deaf club theater to the more choreographed and fast-paced style of the public theater. Deaf and hearing actors moved around on the stage delicately, trying to accommodate each other's presence, but once the performance was spoken, it lost its exclusive signed quality. Like Yiddish theater, deaf club theater faded in the light of professional mainstream performance. Voice technology made public signed performance possible while it diminished what was formerly private. As deaf people became more public and brought their sign language out for others to see, they lost much of what they had privately.

As did the actors in the national theater, deaf people in their everyday lives initially used the spoken voice strategically: to interpret, to explain, to convey what was previously silent and unreachable. But like all forms of communication technology, the spoken voice reorganizes and repositions as it reveals. Voice technology in the community has advanced to where we have professional sign language interpreters who lend voice to those of us who sign. We have captioning where voice is translated to the visual in alphabetic form. Deaf people can connect on the Web to a relay service, where they have access through a webcam to a sign language interpreter who can make voice calls for them. The interpreter dials up another caller on behalf of the deaf person and voice-interprets through the medium of the Internet. As sign is mediated, it is broadcast in voice. In the days of the deaf club, voice was provided by an intimate, a good friend or a relative who knew the sign language and could speak English. Today it can be purchased on demand from a professional. On the Internet, interpreters identify themselves only by number, not by location or name—and they are just as anonymous as voice operators. The intimacy of private lives is replaced by the anonymity of public participation.

The problem of voice in the twenty-first century. The community has changed what it says. Deaf people have changed how they explain themselves. Using technology, deaf people manage the resource of voice for their needs. But what remains is the problem of voice: how do deaf people speak in the time of the microchip and the genome? We find it hard to be heard in the public discussion about prostheses and genetic engineering. This is a problem we share with our disabled colleagues. Here I return to where I began: disability studies and deaf studies have a common project. What is the future of our bodies, and how will science and technology use us to address questions about the future?

The cochlear implant may be a prosthesis, as many of its developers say, but it has also led to an alarming social trend of segregating deaf children—again. There are school districts with separate classrooms for those who have implants. In 1850 deaf schools separated black and white children because of a belief that they could not be educated together, and again in 2004 there are classrooms where deaf children are kept apart from other deaf children in the belief that mixing them would injure their education. Children with implants receive the prosthesis so that they can learn to hear and speak, and in some hospitals sign language is judged not compatible with post-operative treatment: what would be the point of a prosthesis if the patient were to use sign language? Deaf people don't see the two as incompatible, but is their voice being heard? How can they explain that speaking and signing are layered skills and should not be viewed as competing?

In April 2003, the National Institutes of Health announced that scientists had completed the sequencing of the human genome. The Human Genome Project has invited disabled people to say what we think about the scientists' goals for the future. The symbolic conclusion of the genome project represents the beginning of a new age: how will disability

and diversity fare as genetic research moves forward? It has been stated that the goal of understanding the human genome is to relieve human beings of debilitating and fatal genetic conditions. One condition deserving of a cure is deafness. As deafness is cured, the individual is returned to speech. Though the scientists do not say so, a related goal of the project must be to eliminate the need for sign language as well. In the genetic project, sign languages are seen not as among the thousands of human languages of the world but as an adjustment by or even a by-product of those who do not, but should, have speech.

Disability studies and deaf studies have divergent interests, even as they have convergent issues. I believe that deaf people do not view their legacy of segregation in the United States in the same way that other disabled groups do theirs. We who are deaf view our schools' history as constitutive of who we are, even as we acknowledge their troubled past. Our segregated past shaped our social history, from our clubs to our theaters. We build and consume technologies of voice as apparatuses to convey to others what we say. We see the world in visual terms, acknowledging that throughout our history we are, as George Veditz called us, "first, last and for all time, the people of the eye" ("Resolutions" 30). This is why we must have a deaf studies project apart from disability studies.

Yet together these fields of inquiry can be brought to bear on some of the most important issues of our time. Who better to discuss issues of body and society than we who have long suffered social projects inscribed on ourselves? Where better to discuss these issues than in academic programs on university campuses, where the resources of scholars from across disciplines are available? What disability studies and deaf studies can offer are the shared and separate perspectives that

are needed to make some of the most important human issues intelligible to everyone.

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