

17. Do Deaf People Have a Disability?

HARLAN LANE

RECENTLY I ASKED A COLLEAGUE, a university professor I'll call Archibald, whether he thought that Deaf people have a disability. "Of course they do," he answered. "It's common sense." I believe that most hearing people and some Deaf people, too, would say the same thing. When my colleague called the conclusion common sense, he implied that the meanings of the words themselves answered my question. A *disability* is a limitation of function because of an impairment. *Deaf* people are limited in some functions because of an impairment of hearing. Therefore, Deaf people have a disability. That nicely closes the issue for my colleague, but it closes it too soon for us. To travel this issue with the commonsense meanings of the words is to travel with too much a priori baggage. In particular, these meanings take *deaf* and *disability* to be physical attributes of individuals, like their blood pressure or eye color. A great deal follows from this biological understanding of *deaf* and *disability*, including much that Deaf people find hurtful and inimical to their interests. I propose, therefore, to suspend common sense on this issue long enough to explore the concepts of *deaf* and *disability* so we can see what was buried in both the question and the answer.

How did the concept of *disability* arise and what purposes does it serve in our societies? In several of his works, the French philosopher Michel Foucault showed how "bodies are the battlefield"—that is, how political and economic forces in the history of the Western world have fought for control of the human body and its functions.¹ By the eighteenth century, the Western tradition of esteeming the poor was replaced by a political analysis of idleness that continues to the present. To make productive citizens out of idle burdens on the state, it was necessary to distinguish those who *could* not work (the sick and disabled) from those who *would* not work (beggars, vagabonds, and thieves). In 1994 presidential aspirant Phil Gramm, a senator from Texas, confirmed this policy objective of separating the infirm from the indolent: "[We want able-bodied] people riding in the [welfare] wagon," he said, "to get out . . . and help the rest of us pull." The incoming Speaker of the House, Newt Gingrich, agreed.² Likewise, the British government has stated that the products of special education "should be productive if possible and not a burden on the state."³ A 1993 Japanese law similarly aims to make people with disabilities independent and thus employable.⁴

To reduce the numbers of those who could not work and must be given a free ride, the state, starting in the eighteenth century, assumed great responsibility for ensuring the health of the population and could even penetrate the tightly knit family unit and prescribe what should happen to the child's body: hygiene, inoculation, treatments for

disease, and compulsory education.⁵ These practices are generally quite desirable, and they thus formed a continuing basis for the state's claim on the control of bodies. During this era of the rise of modern medicine and the growing intervention of the state in the health of the family, the first national schools for deaf people were founded. In order to ensure that those who could work would do so, a central purpose of those schools was to teach the deaf pupils a trade, removing them from their families where they were poor dependents and converting them into productive members of society. The deaf schools in Europe contained shops to teach trades such as printing, carpentry, masonry, gardening, tailoring, and so on. When schools for deaf people were founded in the United States, they followed this model.⁶

With the arrival of the Industrial Revolution, much larger numbers of people were marginalized; machinery, buildings, and transportation were designed for the normative worker. To separate the able-bodied who could work in these settings from those with disabilities who could not and to regulate the health of children and adults, it was necessary to measure, evaluate, create hierarchies, and examine distributions about the norm. For example, "mental defectives" were considered able to work at simple repetitive tasks, provided their impairment was not too severe. Moderate hearing loss (or unilateral loss) was not an obstacle to most employment, but severe bilateral loss was. Hence the state exercised a more subtle "technology of power" that replaced the brazen power of the king and nobles in feudal society. The technology that has been developed to aid in regulating and rehabilitating includes disciplines such as medicine and surgery, paramedical fields such as optometry and audiology, population studies and applied genetics, psychological measurement, physical anthropology, and rehabilitation and special education. In order to classify people as mentally handicapped, mentally ill, blind, deaf, lame, and so on and hence unable to work in varying degrees, the state requires techniques of measurement and specialists organized into agencies for making those measurements. The more elaborate these special services and benefits are, the greater the need for complex measurements.⁷

The Social Theory of Disability maintains, then, that the category of "people with disabilities" arises out of the work ethic of our capitalist society: People who are not working legitimately are those whose disability precludes employment; they have needs that the rest of society should meet. All other people, such as thieves, vagabonds, and the lazy, are not working for reasons that are illegitimate; they have no claim on our social solidarity, and they should work and be self-sufficient.⁸ Over seventeen million Americans are considered disabled for work, so it is easy to see that the construct of "legitimately not working because of disability" is crucially necessary in our capitalist society.⁹ Clearly, then, disabilities are not simply physical characteristics of the people who have them—they are not like blood pressure, for example. Social issues such as disability are constructed in particular cultures and at particular times in response to the efforts of interested parties. In the United States at present, we designate some forms of human variation as functional limitation arising from an impairment—therefore, a disability—whereas we consider other forms of human variation normal and not a disability at all. Thus we accept as normal human variation—and not disability—wide differences among people in height, but we consider very short people to have a disability;

we accept differences in weight as normal, but gross obesity is a disability; we accept differences in skin color as normal variation, but we consider albinos to have a disability. Differing degrees of alcohol consumption are not a disability, but alcoholism is. We all learn at different rates—that's normal human variation—but mental retardation is a disability. The following are not considered disabilities in the United States today: baldness, nearsightedness, halitosis, and addiction to cigarettes. Mood variation is normal, but we consider mania and depression as mental illnesses. An addiction to pipe smoking is not a disability, but an addiction to crack smoking is. Not only is it hard to tell disabilities from normal variation, but today's disability may be tomorrow's normal variation and vice versa. Alcoholism has gone from moral flaw to disability. Homosexuality from moral flaw to disability to minority rights. Child abuse from moral flaw to disability. Mild mental retardation from normal human variation to disability.

What then determines whether some form of human variation is a disability? The answer is—norms and the technologies of normalization. Take height, for example. What matters to a culture is not so much the physical attribute of so many feet or meters from head to toe but rather the cultural counterparts *short* and *tall*, which are relative to a norm. People who are much shorter or taller than the average *in a particular culture and a particular era* are viewed as having a disability in that culture and era. That is, they are seen as having an impairment—their very short or tall stature—that leads to restricted functioning. Very short people cannot readily reach keyboards, objects on standard countertops, parts of machinery, and so on. Very tall people cannot fit into airplanes readily, have difficulty driving standard cars, and the like. The view that people with abnormal heights have a disability sets the stage for the intervention of experts—the technologies of normalization. These experts will investigate the problem, teach others how to do so, propose remedies, administer medical and surgical treatment and rehabilitation, teach others how to do that, measure the remaining problem and determine eligibility for government-prescribed benefits, lobby government for those benefits, and so on.

Here is how the technologies of normalization have operated in the arena of height. In the United States and Great Britain nowadays, a large number of children are receiving injections of growth hormone, costing over \$20,000 a year per child. Shortness was never viewed as a medical condition until the technologies of normalization came up with a treatment. Thus the disability did not lead to the treatment; rather, the treatment led to the disability. Shortness became a disability, once a treatment was available, because if doctors administered a treatment, there must be a disorder to treat. The synthetic growth hormone has some nasty side effects and is expensive. Nevertheless, the market for it in the United States is estimated to be \$350,000,000 annually and growing.¹⁰ Doctors working for Genentech, Inc., which manufactures the hormone, claim that the shortest 3 percent of the population needs their treatment. Ninety thousand children born annually make up the shortest 3 percent of the U.S. population, which corresponds to a potential annual market of \$8–10 billion. Best of all for Genentech, there will always be children with this so-called impairment of growth, for no matter how tall our whole population becomes, there will always be a shortest 3 percent. According to Genentech doctors, however, treating these children is not a minor matter

of cosmetics: statistics show that our society is "heightist," and short people do not get a fair deal.¹¹ Thus what sustains the whole enterprise is the biologizing of a social state of affairs. Discrimination against short people becomes rooted in *them*, not us, but we can treat the problem *they* have. Thus, socially rejected difference is reified as a treatable biological condition, and the responsibility for social inequality is shifted onto the individual who is said to have that treatable condition. This minimizes the need for change in the society at large, which pleases both the public, happy to leave the problem to the technologies of normalization, and also the technologies themselves, which, like all professions, tend to be self-perpetuating and self-promoting (audiology, for example, is on the threshold of having its services mandated for every child born in the United States from here on out).

The only group that clearly doesn't gain from the medicalization of social difference is its targets. In 1998 the British medical journal *Lancet* reported that short children whose height was increased two to three inches by treatment with the synthetic product Somatropin received no psychological benefits.¹² Researchers at Southampton Hospitals in England treated seven short girls with daily injections from age eight to fourteen. The cost of the treatment, paid for by drug companies, worked out to \$46,000 per stimulated inch of growth—not to mention some 2,500 injections per child. A comparison group of short girls who did not receive the treatment was just as happy and well balanced as the treated girls although they were three inches shorter at age sixteen. The team is now repeating the investigation on short boys.¹³

Consider another example of a socially rejected difference reified for gain, thereby shifting the responsibility for inequality onto the individual. In this case, the socially rejected differences are differences in social class and skin color. In the late 1800s Francis Galton, son of a Birmingham banker, undertook a study of wealthy British families like his own and found that eminence ran in such families, which he attributed to superior heredity. He rejected the idea that a family with three generations of lawyers, for example, owed that success to superior education, family connections, and other such environmental explanations. Instead, much inspired by Charles Darwin's theory of evolution, Galton thought eminence to be mainly the result of biological differences in intelligence, the result of family heredity, and he tried to find biological correlates of eminence, such as head size, but was unable to. With the invention of Binet's IQ test at the turn of the century, scientists such as Galton, who believed that class differences were the result of innate differences in intelligence, finally had a measure of innate ability, and they found widespread evidence of a correlation between IQ scores and social success. For example, the unemployed and uneducated generally scored lower in IQ than people in the professions. Some modern-day scientists offer the same explanation for the disadvantaged condition of many blacks, attributing it to an innate deficiency in black intelligence.¹⁴ To validate their claim, these scientists cite a fifteen-point difference in black and white scores on IQ tests. However, if such a difference exists, after correcting for the cultural bias in the tests, it may simply reflect the effects of being classed in our society as black rather than white: it may reflect social discrimination rather than heredity. Thus, a socially rejected difference—lower social class—has been reified as diminished innate intelligence, thereby shifting the responsibility for that difference onto the individual and minimizing the need for social change.

The technology of normalization organized around IQ is large indeed. IQ testing, especially the massive testing of two million recruits during World War I, changed psychology from a largely academic subject to one that was widely respected as having real social utility.¹⁵ The IQ test was created by experts, administered by experts, and interpreted by experts. IQ testing of nearly two million World War I recruits yielded an alarming result: the average white American had the mental age of a thirteen-year-old; black Americans scored even lower. The IQ test, with these alarming results, helped to lay the foundations for special education. The experts in this technology of normalization computed a distribution around a norm and assigned those children who fell a specified number of units below the norm to specialized institutions on the grounds that technology had revealed their inner deficit, although that deficit frequently lacked any outer sign. The norm was arbitrary. In fact, other IQ tests would have classed as normal more than half of the children labeled as morons requiring institutional care.¹⁶ The aggrandizement of the new "special education" proceeded rapidly in the following decades, encouraged by regular classroom teachers who were delighted with the resulting homogenization of their classrooms. The proportion of children enrolled in special education has grown a hundredfold in Finland in the last five decades;¹⁷ in some states in Australia, it has grown fifteenfold.¹⁸ In Great Britain, the *Warnock Report*, a comprehensive survey of special education "needs" in 1978, concluded that as many as one in five children would need those services and called for a major expansion of the special education establishment.¹⁹ Thus is the majority protected from social deviation to the advantage of the technologies of normalization.

The technologies of normalization that developed around this particular reification in biology of social differences—IQ—included not just research, measurement, institutionalization, and rehabilitation but also eugenic measures to purge society of this unwanted burden. Early in this century, American psychologists found that the average intelligence of immigrants was declining now that their origins had shifted from northern to southern Europe—two out of five in steerage were feeble-minded, they claimed—and they successfully urged stricter immigration policies.²⁰ They claimed that poorer people had not only lower IQ but also larger families so that over time the "bad germ plasm" would gain ground over the innate intelligence of the better classes. Thus, numerous eugenic societies sprang up in the United States and Great Britain, and many discussions of proposals for improving society through selective breeding ensued. Among them were sterilizing the unfit; educating the unfit so they would agree to voluntary sterilization; restricting marriage among the unfit and encouraging it among the fit; and tax rebates for maternity costs and child rearing in meritorious families.²¹ The eugenic principle of selection on the basis of individual biological and mental quality was transformed into a principle of racial or ethnic-group selection in immigration, and behavior that was outside the bounds of prevailing middle-class standards was taken as evidence of biological and hence hereditary lack of fitness.²²

With these reflections and the examples of height and IQ, we are in a position now to characterize *disability* more accurately and as it turns out in quite a different way from its dictionary definition. A disability is a classification of a physical, behavioral, or mental difference from the norm that is attributed to biological causes in a particular culture in a given era, as a result of the interventions of interested parties.

As with *disability*, we want to unpack the meaning of *deaf* and observe what the commonsense meaning of the word fences in and fences out. In everyday discourse, when we say that someone is deaf, we call on a socially constructed set of meanings. One of those meanings in common parlance is that deaf people lack a vital sense. Another meaning is that these are people whose choices are restricted. In many cultures when you say someone is deaf, you are understood to mean that that person can aspire to only a limited education and that their choices in employment will be severely restricted, too. In some countries, deaf is an explanation of why a child cannot go to school at all. In others, it is an explanation of why a child can profit from only elementary education; in still others it explains why university studies are not possible. Even in the United States, with its uniquely long history of higher education for deaf people, sentences such as "John didn't go to the university because he's short" strike us as illogical, but sentences such as "John didn't go to the university because he's deaf" do not. Likewise for the world of work. Sentences of the type "Because she's deaf, Mary couldn't be a politician like her mother" do not give most Americans pause. The underlying meanings that these explanations refer to have been called *audism*.²³ Like racism and sexism, audism insists that inherent biological factors determine individual traits and capacity. One of the greatest handicaps in being deaf is the reduced range of choices that is open to the deaf person. In many countries deaf people do not have the right to an education, to social services, to drive a car, to employment at the level of their skills, or to the free use of their language.²⁴ The loss of choices is largely the result of the social construction of what it means to be *deaf*—the result of audism—rather than of any sensory limitation that deaf people have. In that sense, our society largely creates the problems of being deaf.

The widespread tendency in our society to reify in individual biology what are in fact social conditions—the discrimination against short people, poor people, black people, Southern Europeans—alerts us at once to the hidden meanings of audist claims. In 1996 a leading American journal of ear surgery published the most extensive defense yet of the ethics of cochlear implant surgery on deaf children. Explaining why such surgery is necessary, the authors claim that deafness is "the most disabling of disabilities," that deaf children incur very high costs in education, and that deaf adults cost society a lot of money, too, because they need help gaining access to events and other help such as interpreters.²⁵ The message is that there is a serious problem because of the deviant physical makeup of the deaf child, and surgery is justified. The aim of normalizing surgery is to reduce human variation: to reduce or eliminate not only those differences that cause physical suffering but also those that underpin ways of life with which the concerned people are happy, people such as intersexuals, conjoined twins, dwarfs, and Deaf people.²⁶ Likewise blaming the child's hearing and asserting the need for technological services, a British audiology text contends that the entire family with a deaf child is a family with a disability and that the disabled family requires "saturation services" from numerous professionals like the authors of the book.²⁷ This is indeed claims making, the "politics of description." Nothing is said here of Deaf Culture, of the power and beauty of sign language, of the history of oppression of Deaf difference, of culturally Deaf people's above-normal abilities in spatial perception and cognition,²⁸ and so on.

Never is it mentioned that Deaf parents (and many hearing parents) raise Deaf children very well without surgery, without saturation services, and indeed without any special intervention.

The explanatory power of *deaf* is reinforced by the media. Movies and books have tragic deaf characters whose predicament is attributed to their being deaf. But positive images also reinforce the explanatory power of *deaf*. Deaf people are held up as admirable for having overcome or minimized their deafness. They took their deafness as a challenge that they successfully confronted. This image, too, reinforces the idea of *deaf* as an explanation. Both negative and positive images are emergent constructions of audism. What can this concept of *deaf* really explain? It cannot justify limited career choices because deaf people are found in virtually all fields. It cannot explain limited educational achievement because there are deaf PhDs, deaf professors, and so on. It cannot justify the livelihood of countless hearing professionals because, as mentioned, Deaf parents commonly raise Deaf children quite successfully without those professionals. The underlying idea is that mere sensory difference has vast explanatory power, yet it does not. The assumption that it does is reinforced by hearing politicians, doctors, and parents.

The stereotypes of audism are an expression of audism but not the audism itself. What is the source of the belief that being a deaf person entails an inherent biological limitation? Why is *deaf* associated with loss rather than difference and gain (different language, different culture, etc.)? I submit that it is because the society that has elaborated the concept of *deaf* is largely hearing and conceptualizes *deaf* as a loss of hearing. Indeed, the difference in hearing of a person born deaf and one born hearing is called "hearing loss," although the deaf person didn't lose anything. The idea that sensory difference is loss is reinforced by the limitations of hearing people who lose their hearing. Then, too, some authors have argued that deafness cannot just be mere difference because it involves the loss of a sense that is essential for survival. They believe that our species has survived because of its common features, including the five senses. In fact, the common features of our species, such as hearing, may reflect the vicissitudes of evolution eons ago, and, in any event, do not individuals with fewer common features have equal claim on our allegiance? Do they not have the right to value their atypical physical constitutions even if they were associated with less reproductive fitness?

Deaf organizations sometimes attack the manifestations of audism. They campaign against mainstreaming, against cochlear implant surgery on deaf children, and against discrimination in employment. The activism attacks the expressions of the audist beliefs but not the beliefs themselves, which are part of the meaning of the word *deaf* (deaf people are lacking; they have a biological flaw) and thus will continue to fuel oppressive practices. A similar sort of analysis applies to sign language. When people say that sign language is primitive or they express surprise that it is not universal, they are simply unfolding the socially constructed meaning of *sign language*, which is, according to *Webster's New Collegiate Dictionary*, "a system of hand gestures used for communication (as by the deaf); an unsystematic method of communicating chiefly by manual gestures used by people speaking different languages." Similarly, a campaign to allow sign language in the classroom can encounter determined resistance because it does

not attack the source of the exclusion, which is the culturally constructed meaning of *sign language*.

Deaf organizations today have embraced the term *Deaf*, perhaps in part in the same "in your face" spirit that black people adopted *black* or that an organization of gay activists has adopted the name Queer Nation. Some Deaf leaders try to mark the distinct significance of *cultural* deafness—to set it apart from the general English usage of the word *deaf*—by capitalizing the *D*. The older terms for this cultural group were *deaf-mute* (as in the *Deaf-Mute Journal*) and *Silent* (as in the magazine *Silent Worker*). These terms, like the capital *D*, made a helpful distinction. Mute or Silent people are those who, for the most part, do not speak. This accurately excluded from the group hearing people who lost their hearing but who continued to speak and did not change cultural affiliation. An advantage of *mute* and *Silent* over the capital *D* is that the capital *D* is perceptible only in writing. Some culturally Deaf scholars have referred to the members of their culture as "the Visual People," but that label has not made inroads against *Deaf*.

I have argued that, for most hearing people, the term *deaf* has at the core of its meaning a loss, a flaw. Now, what does *deaf* mean to Deaf people? Because Deaf people have their own language and culture, and such ideas are culturally constructed, it is not surprising that different meanings, positive ones, are embedded in the term *deaf* in Deaf Culture. (If cultures dominated by hearing people value being hearing, must we not expect that cultures dominated by Deaf people value being Deaf? Indeed, is there any culture in the world that does not value the predominant physical makeup of its members?) According to my Deaf informants, *Deaf* means "like me"—one of us—in significant cultural ways. A Deaf person values being Deaf and possesses the other attitudes, values, mores, and knowledge particular to that culture. Thus, something positive lies at the core of the meaning of Deaf, and there is no implication of loss.

With these reflections and examples, we are in a position to characterize *deaf*, as it applies to members of the Deaf world, in quite a different way from its dictionary definition. *Deaf* refers to a member of a linguistic and cultural minority with distinctive mores, attitudes, and values and a distinctive physical constitution. We refer to the members of that culture as Deaf and to the culture itself as the Deaf world; these are glosses of the signs in American Sign Language (ASL) with which Deaf people refer to themselves and their culture, respectively. We also follow the Deaf world practice in referring to children of any age as capital-D Deaf who have, for whatever reason, the physical constitution characteristic of this minority—that is, they rely so much more on vision than on hearing that they communicate most readily, given the opportunity, in a natural sign language. This practice also reflects the logic of cultural attribution in hearing society, which is based on the child's likely life trajectory given its physical makeup. We call children Native American, African American, Asian American, and so forth long before they have learned any language or culture, and we do not ask to see their parents before deciding on their cultural membership, so such attributions are clearly based on physical makeup.

Poor Archibald! Asked "Do deaf people have a disability?" he answered that common sense says they do. But now we see that, far from common sense, the question makes no sense. A disability is a social classification in a particular culture at a particular

time, the outcome of a power struggle among interested parties. And we see that Deaf, in the context of our present concerns, refers to a distinctive culture, not to loss or incomprehension. Perhaps Archibald would have been wiser to answer my question, "Do deaf people have a disability?" by saying "I can't answer your question because a disability is not something you have; it's a label you acquire." Well, then, *should* Deaf people seek this *disability* label assigned to them by the technologies of normalization or at least acquiesce in it, or should they actively resist it?

It seems to me (but then I'm not Deaf) that there are many reasons to resist the label of *disability*. In the first place, in the framework of their culture, Deaf people reject the suggestion that they have an impairment or a disability (the ASL sign that translates roughly as *disability* does not include being Deaf). In contrast, leaders in the disability rights movement say they themselves do have a disability (of course, there are exceptions in each group). These disability rights leaders call for ambivalence about their impairment; individually they want it positively valued as a part of who they are. At the same time, it is the result of poverty, war, disease, or accident, so they want it negatively valued and support measures that reduce the incidence of the impairment.²⁹ But the Deaf world is not ambivalent; its members characteristically think it is a fine thing to be Deaf and favor more of it. Unlike most expectant parents with disabilities, expectant Deaf parents characteristically hope to have children with whom they can share their language, culture, and unique experiences—that is, they hope to have Deaf children.³⁰

So Deaf people are fundamentally unlike people who say they have disabilities, for to Deaf people the proposal that they have a disability "just doesn't compute."³¹ Disowning the disability label would therefore be the honest thing to do. In the second place, consider what the disabilities rights movement seeks: above all, better medical care, rehabilitation services, and personal assistance services (e.g., help with personal hygiene, dressing, and eating).³² Deaf people do not attach particular importance to any of these services—no more than any other able-bodied group. Whereas the disability rights movement seeks independence for people with disabilities, Deaf people do not have any more concern with independent living than people in general. Deaf people cherish interdependence with other Deaf people. Whereas people with disabilities seek total integration into society at large, Deaf people cherish their unique identity and seek integration that honors their distinct language and culture. Integration of Deaf children into hearing schools and classes is an anathema to the Deaf world. The specialized schools for Deaf people, especially the residential schools, were the setting in which most Deaf adults acquired fluent (manual) language and socialization. Those specialized schools and, after graduation, the Deaf clubs with their athletic, literary, political, and social programs have provided most Deaf people in America, despite their having hearing parents, with the generational continuity that is essential for a rich culture.

So Deaf people generally do not see themselves as disabled nor do they seek what people who say they are disabled seek. Disowning the disability label is therefore the prudent thing to do because the provisions that society makes for people with disabilities often do not suit the interests of Deaf people and may even run counter to them. Furthermore, because of the commonsense meaning of disability, when Deaf people embrace that label they encourage the untiring efforts of the technologies of normal-

ization to reify in biology what are in fact social disadvantages of Deaf people. This deflects attention from the need for social reforms. Worse yet, this disability label encourages the technologies of normalization in their eugenic and surgical programs aimed at eliminating or severely reducing the ranks of culturally Deaf people. Because the hearing agenda for Deaf people is constructed on the principle that members of the Deaf world have a disability and because our society seeks to reduce the numbers of people with disabilities through preventative measures, hearing people have long sought measures that would reduce the number of Deaf people, ultimately eliminating this form of human variation and with it eliminating the Deaf world. The chairman of a U.S. National Institutes of Health planning group acknowledged this in an interview with the *New York Times*: "I am dedicated to curing deafness. That puts me on a collision course with those who are culturally Deaf. That is interpreted as genocide of the Deaf."³³

Two measures that would reduce the numbers of Deaf people and are actively pursued today in many lands are eugenics and cochlear implant surgery on young Deaf children. The professions that advocate such extreme measures are clearly calling on the commonsense understanding of *deaf* as disability in promoting their programs.

Hearing efforts to eugenically regulate childbearing by Deaf people have a long history. The central purpose of the large-scale oral education of Deaf children that began in the last century and continues today in many lands was, according to U.S. leaders, to discourage reproduction by Deaf people by discouraging their socializing and marriage.³⁴ This was also a central goal of the day-school movement, a goal championed by one of the leaders of the American eugenics movement, Alexander Graham Bell. At first Bell saw in the oral education of Deaf people—based on speech and lipreading and prohibiting sign language—a means of encouraging them to marry hearing people. But it soon became clear that Deaf schoolmates intermarried no matter whether their residential school used ASL or spoken English. Thus, measures would be required to keep Deaf schoolmates apart physically so they would not marry and procreate more Deaf children. That meant boarding the Deaf pupils at home and instructing them in small classes to minimize contact among Deaf people. Bell told lawmakers that day schools allow "keeping deaf-mutes separated from one another as much as possible."³⁵ He warned of the dangers of Deaf congregation at the state residential schools.

Oral education and day-school classes are rather indirect methods of regulating Deaf childbirth. Hearing people have embarked on direct eugenics of Deaf people as well. The twentieth century witnessed movements in the United States and Germany, for example, to sterilize Deaf people by law and to encourage them to seek voluntary sterilization or abstain from childbearing. The legal initiative in the United States had limited success, but its well-publicized pursuit led untold numbers of Deaf people to abandon plans for marriage and reproduction or to submit to voluntary sterilization, and the clamor about Deaf eugenics also led untold numbers of hearing parents to have their Deaf children sterilized. Alexander Graham Bell, head of the Eugenics Section of the American Breeders Association (later the American Genetics Association), laid the groundwork for such efforts in his numerous statistical studies and censuses of the Deaf population in the United States and especially in his 1883 *Memoir upon the Formation of a Deaf Variety of the Human Race*, which he printed privately and distributed widely.

Moreover, he presented this broadside against Deaf Culture and Deaf intermarriage to the National Academy of Sciences on his election to that body, giving the false impression that it was sanctioned by the academy and was scientifically valid. In this memoir, Bell warned that "the congenital deaf-mutes of the country are increasing at a greater rate than the population at large; and the deaf-mute children of deaf-mutes at a greater rate than the congenital deaf-mute population." Bell attributed the problem to sign language, which "causes the intermarriage of deaf-mutes and the propagation of their physical defect."³⁶ The Eugenics Section prepared a model sterilization law and promoted it in the nation's state legislatures; it called for sterilization of feeble-minded, insane, criminalistic, deaf, and other "socially unfit" classes.³⁷ By the time of the German sterilization program, some thirty states in the United States had sterilization laws in force. However, Bell's lobbying efforts were unsuccessful, and none of the laws specifically included Deaf people.

The purpose of the eugenics movement with respect to Deaf people, the measures aimed at discouraging their socialization, intermarriage, and reproduction, was not so much to achieve those goals, which were largely unachievable and would be ineffective if achieved. After all, most Deaf children have hearing parents, as Bell well knew, so even if he had had his way and no Deaf adults had Deaf children that would not seriously reduce the numbers of Deaf children. What then was Bell's purpose in promoting eugenic measures with Deaf people? I submit that it was to reinforce a certain conceptualization or "construction" of Deaf people, one that was linked to the construction of people with impairments such as feeble-mindedness and to a particular technology of normalization—oralism—with its own authorities, legislation, institutions, and professions. Moreover, the eugenics campaign marked the Deaf world as an important social problem requiring expertise, one that had been previously overlooked, much to the danger of society. In this respect, the claims making closely paralleled the movement to awaken society to the dangers of mentally retarded people in our midst. As psychologists and superintendents of institutions for the feeble-minded stood to gain from the recognition of the newly discovered social problem of mild retardation, so a competent authority that stood to gain from the construction of Deaf people as a newly discovered menace was the burgeoning organization Bell had founded, the American Association to Promote the Teaching of Speech to the Deaf (AAPTSD). In 1969 this association, now known as the Alexander Graham Bell Association for the Deaf, republished Bell's *Memoir*, praising its "perceptive insights."³⁸ The eugenics movement as it concerned Deaf people worldwide has received regrettably little study.³⁹ When National Socialism came to power in Germany, fully forty organizations of Deaf people in Berlin were combined into two; the treasuries of the original organizations were confiscated; the Jewish Deaf Association was prohibited; and Jewish members of all other Deaf organizations were expelled. Teachers of Deaf students advocated adherence to the hereditary purity laws, including the sterilization of congenitally Deaf people. Deaf school children were required to prepare family trees, and the school reported those who were congenitally Deaf or who had a Deaf relative to the department of health for possible sterilization. Leaders of the unified Deaf organization and the Deaf newspaper, themselves late-deafened, endorsed the sterilization campaign.⁴⁰

The German sterilization law that went into effect in 1934 provided that "Those hereditarily sick may be made unfruitful [sterilized] through surgical intervention. . . . The hereditary sick, in the sense of this law, is a person who suffers from one of the following diseases . . . hereditary deafness."⁴¹ The 1933 census showed forty-five thousand "deaf and dumb" persons in a total population of over sixty-six million. An estimated seventeen thousand of these Deaf Germans, a third of them minors, were sterilized. In 9 percent of the cases, sterilization was accompanied by forced abortion. An additional sixteen hundred Deaf people were exterminated in concentration camps in the 1940s; they were considered "useless eaters," with lives unworthy of being lived.⁴² As in the United States, the medical profession was the certifying authority for forced sterilization. And as in the United States, such legislation may have been concerned more with constructions of social problems and the identification of competent authority than with measures for their practical resolution.

In 1992 researchers at Boston University announced that they had identified the "genetic error" responsible for a common type of inherited deafness. The director of the National Institute on Deafness and Other Communication Disorders [*sic*] called the finding a "major breakthrough that will improve diagnosis and genetic counseling and ultimately lead to substitution therapy or gene transfer therapy."⁴³ Thus a new form of medical eugenics applied to Deaf people was envisioned, in this case by an agency of the U.S. government. The primary characteristics of Deaf people with this genetic background are numerous Deaf relatives, sign language fluency, facial features such as widely spaced eyebrows, and coloring features such as a white forelock and freckling.⁴⁴ For such characteristics to be viewed not as normal human variation in physiognomy, coloring, and so on but as a "genetic error," some of the common features must clearly be construed as signs of a disease or infirmity. However, according to a leading medical geneticist, the "sole detrimental feature" of the syndrome is that some people with this gene are Deaf.⁴⁵ Within the culture of the Deaf world, then, this cannot be a disease.

The technologies of normalization seek not only to reduce Deaf births but also to change the physical makeup of the Deaf child through surgery so that that child is, to whatever extent possible, a little more like a hearing child or, to be more accurate, like a child with a hearing impairment. There is consensus among ear surgeons and audiologists that a child with a cochlear implant is "severely hearing-impaired,"⁴⁶ and some comparisons with hearing-aid users even place many of them in the category of those with a profound hearing impairment.⁴⁷

If the Deaf child has a serious disability, then surely an operation that tries to reduce that disability is justified, even if it has limited success, even if its risks are not well understood, and even if it is very expensive. This consequence of the disability classification applied to culturally Deaf children is fraught with danger for those children and the Deaf world. The surgery is of unproven value for the main benefit sought, spoken language acquisition, while the psychological, social, and linguistic risks have not been assessed but appear ominous.⁴⁸ Thus the surgery is innovative, but innovative surgery on children is unethical.⁴⁹ Moreover, if there were highly effective implants—and one day there may well be—the ranks of the Deaf world would presumably diminish. It is unethical to take steps that tend to reduce the ranks of a minority culture, and it violates

international law,⁵⁰ but the disability categorization of *deaf* is so intuitive here that few hearing people see the danger in allowing cochlear implant programs to proceed at an accelerating pace.

All in all, then, there are many powerful arguments in favor of Deaf people's resisting the disability classification that the technologies of normalization seek.⁵¹ But therein lies a dilemma. Government and the technologies of normalization have linked granting Deaf people their fundamental rights as citizens to their colluding in classifying them as people with a disability. In those countries where Deaf people can get interpreters, those services are organized under a disability umbrella. In fact, able-bodied Deaf people in the United States and some other countries can get cash merely for agreeing that they are disabled and registering as such. Likewise, Deaf children can get schooling only under the disability classification. The dilemma is that Deaf people want access and as citizens in a democracy have a right to access—access to public events, government services, and education—but when they subscribe to the disability definition in order to gain access, they undermine their struggle for other rights, such as an education for Deaf children using their best language, an end to implant surgery on those children, and an end to efforts to discourage Deaf births in the first place. The technologies of normalization, through extensive lobbying, have shaped those government policies that have created this dilemma for Deaf people. With enough disincentives to change, Deaf people may tolerate the misclassification and indeed may even appear to support it, as when they demand their rights under the Americans with Disabilities Act. The stronger the link between Deaf and disability, the better the prospects for the professions predicated on that link.

Yet, Deaf activism may turn things around. The constructions of numerous social groups are different today from what they were generations ago because of the groups' activism in changing social understanding. Blacks in America are no longer property—they are citizens. Gays and Lesbians are no longer distinguished by a defect but rather are seen as a minority set apart by a characteristic of their birth, like blacks and women. Native Americans are no longer understood as savages; women are no longer thought to be inherently the weaker sex, whose life roles must center around child rearing. Deaf people can come to be understood not as a disability group but as the possessors and protectors of a great cultural heritage, a beautiful language, numerous art forms, and an eloquent history. That will require Deaf people to mount a vigorous effort to oppose the claims making of the technologies of normalization. Indeed, many in those professions and in the social sciences and humanities would join Deaf people in their opposition. Is an antidefamation league needed to promptly rebut such self-serving disparagement of Deaf people as "a catastrophe,"⁵² a people in need of saturation services, implant surgery, and eugenic gene therapy? Is the time right for Deaf people to mount a major marketing effort, one that involves, for example, advertising, public service announcements, celebrity spots on TV, stories for the media, and a source of pro-Deaf information for the nation? Such an effort would target outreach to parents, doctors, and legislators as well as the general public, helping them to understand the positive value of this form of human variation. In the nineteenth century, black leader Frederick Douglass said this about a comparable effort for his minority: "Oh, had I the

ability, and could I reach the nation's ear, I would today pour out a fiery stream of biting ridicule, blasting reproach, withering sarcasm, and stern rebuke. For it is not light that is needed, but fire; it is not the gentle shower, but thunder."⁵³ Unless Deaf people challenge the culturally determined meanings of *deaf* and *disability* with at least as much vigor as the technologies of normalization seek to institutionalize those meanings, the day will continue to recede in which Deaf children and adults live the fullest lives and make the fullest contribution to our diverse society.

Notes

1. Michel Foucault, *Power/Knowledge: Selected Interviews and Other Writings, 1972-1977* (Brighton, Sussex: Harvester Press, 1980).
2. "Welfare Helps Kids," *USA Today*, November 16, 1994, 12A.
3. Department of Education and Science, *Special Educational Needs (Warnock Report)* (London: Her Majesty's Stationery Office, 1978).
4. Osamu Nagase, "Disabled Persons' Fundamental Law in Japan" (paper presented at the Disability Rights Symposium of European Regions, Southampton, England, 1995).
5. Foucault, *Power/Knowledge*.
6. Harlan Lane, *When the Mind Hears: A History of the Deaf* (New York: Random House, 1984).
7. Susan Gregory and Gillian M. Hartley, eds., *Constructing Deafness* (London: Pinter, 1991).
8. Paul Abberley, "The Concept of Oppression and the Development of a Social Theory of Disability," *Disability, Handicap and Society* 2 (1987): 5-19. M. Oliver, "Multispecialist and Multidisciplinary: A Recipe for Confusion? Too Many Cooks Spoil the Broth," *Disability, Handicap and Society* 6 (1991): 65-68.
9. U.S. Department of Commerce, *Statistical Abstract of the United States* (Washington, D.C.: Superintendent of Government Documents, 1999).
10. "Teva to Market," *Business Wire*, March 30, 2000, <http://www.businesswire.com>.
11. Beth Werth, "How Short Is Too Short?" *New York Times Magazine*, Section 6, June 16, 1991, 14-17, 28-29, 47.
12. E. McCaughey, J. Mulligan, L. Voss, and P. Betts, "Randomised Trial of Growth Hormone in Short Normal Girls," *Lancet* 351 (1998): 940-44.
13. "Researchers at Southampton University Hospitals," *Science News*, April 25, 1998, 271. A. B. Downie, J. Mulligan, E. S. McCaughey, R. J. Stratford, P. R. Betts, and L. D. Voss, "Psychological Response to Treatment in Short Normal Children," *Archives of Disorders of Childhood* 76 (1996): 92-95.
14. Richard Herrnstein and Charles Murray, *The Bell Curve* (New York: Free Press, 1994).
15. M. L. Andersen, "The Many and Varied Social Constructions of Intelligence," in *Constructing the Social*, ed. T. R. Sarbin and J. I. Kitsuse (London: Sage, 1994), 119-38.
16. S. A. Gelb, "Social Deviance and the 'Discovery' of the Moron," *Disability, Handicap and Society* 2 (1987): 247-58.
17. J. Kivirauma and O. Kivinen, "The School System and Special Education: Causes and Effects in the Twentieth Century," *Disability, Handicap and Society* 3 (1988): 153-65.
18. G. Fulcher, "Australian Policies on Special Education: Towards a Sociological Account," *Disability, Handicap and Society* 1 (1986): 19-52.
19. Department of Education and Science, *Special Educational Needs*.
20. Stephan Chorover, *From Genesis to Genocide* (Cambridge, Mass.: M.I.T. Press, 1979). H. H. Goddard, "Mental Tests and the Immigrant," *Journal of Delinquency* 2 (1917): 243-77.
21. Lane, *When the Mind Hears*.
22. Daniel Kevles, *In the Name of Eugenics: Genetics and the Uses of Human Heredity* (New York: Knopf, 1985).

23. Tom Humphries, "Communicating across Cultures: Deaf/Hearing and Language Learning" (PhD diss., Union Graduate School, Cincinnati, 1977). Harlan Lane, *The Mask of Benevolence: Disabling the Deaf Community*, 2nd ed. (San Diego: DawnSignPress, 1999).
24. M. Joutsalainen, *World Federation of the Deaf Survey of Deaf People in the Developing World* (Helsinki: World Federation of the Deaf, 1991).
25. Thomas Balkany, A. Hodges, and K. Goodman, "Ethics of Cochlear Implantation in Young Children," *Otolaryngology: Head and Neck Surgery* 114 (1996): 751.
26. Alice Dreger, *Hermaphrodites and the Medical Invention of Sex* (Cambridge, Mass.: Harvard University Press, 1998). A. Draeger, "The Limits of Individuality: Ritual and Sacrifice in the Lives and Medical Treatment of Conjoined Twins," *Studies in the History and Philosophy of Biological and Biomedical Sciences* 29 (1998): C:1-29. Joan Ablon, *Little People in America: The Social Dimensions of Dwarfism* (New York: Praeger, 1984). Harlan Lane, "The Cochlear Implant Controversy," *World Federation of the Deaf News* 2, no. 3 (1994): 22-28.
27. Ivan Tucker and Michael Nolan, *Educational Audiology* (London: Croom Helm, 1984). Quoted in Gregory and Hartley, *Constructing Deafness*, 97.
28. Karen Emmorey, *Language, Cognition, and the Brain: Insights from Sign Language Research* (Mahwah, N.J.: Lawrence Erlbaum Associates, 2001).
29. Abberley, "Concept of Oppression."
30. Gaylene Becker, *Growing Old in Silence* (Berkeley and Los Angeles: University of California Press, 1980). R. Saltus, "Returning to the World of Sound," *Boston Globe*, July 10, 1989, 27, 29.
31. Tom Humphries, "Deaf Culture and Cultures," in *Multicultural Issues in Deafness*, ed. K. M. Christensen and G. L. Delgado (White Plains, N.Y.: Longman, 1993), 14.
32. Joseph P. Shapiro, *No Pity: People with Disabilities Forging a New Civil Rights Movement* (New York: Times Books, 1993).
33. "Pride in a Soundless World," *New York Times*, May 16, 1993, section 1, p. 1.
34. John V. Van Cleve, "Nebraska's Oral Law of 1911 and the Deaf Community," *Nebraska History* 65 (1984): 195-220.
35. Robert V. Bruce, *Alexander Graham Bell and the Conquest of Solitude* (Boston: Little, Brown, 1973).
36. Alexander Graham Bell, *Memoir upon the Formation of a Deaf Variety of the Human Race* (New Haven: National Academy of Sciences, 1883; repr. 1969), 40, 44.
37. Harlan Lane, "Cochlear Implants: Their Cultural and Historical Meaning," in *Deaf History Unveiled*, ed. John Van Cleve (Washington, D.C.: Gallaudet University Press, 1993), 272-91.
38. Victor Goodhill, "Foreword," in Bell, *Memoir upon the Formation of a Deaf Variety of the Human Race*, unnumbered page.
39. But see Horst Biesold, *Crying Hands: Eugenics and Deaf People in Nazi Germany*, trans. Will Sayers (Washington, D.C.: Gallaudet University Press, 1999). Donna Ryan and John Schuchman, eds., *Deaf People in Hitler's Europe* (Washington, D.C.: Gallaudet University Press, 2002).
40. J. Muhs, "Followers and Outcasts: Berlin's Deaf Community under National Socialism, 1933-1945," *Collage* 33 (1996): 195-204.
41. W. W. Peter, "Germany's Sterilization Program," *American Journal of Public Health* 243 (1934): 187.
42. Biesold, *Crying Hands*. Cited in W. Higgins, ed., "La Parole des Sourds," *Psychoanalystes* 46-47 (1993): 1-216.
43. "BU Team Finds Genetic Cause of Waardenburg Syndrome," *Deaf Community News*, March 1992, 6.
44. G. R. Fraser, *The Causes of Profound Deafness in Childhood* (Baltimore: Johns Hopkins University Press, 1976).
45. George R. Fraser, "Hearing Loss: Genetic Causes," in *Gallaudet Encyclopedia of Deaf People and Deafness*, ed. John Van Cleve (New York: McGraw-Hill, 1976), 20-23.
46. Mary Joe Osberger and D. Kessler, "Issues in Protocol Design for Cochlear Implant Trials in

- Children: The Clarion Pediatric Study," *Annals of Otolaryngology, Rhinology and Laryngology* 9, suppl. (1995): 337-39.
47. R. T. Miyamoto, K. I. Kirk, S. L. Todd, A. M. Robbins, and M. J. Osberger, "Speech Perception Skills of Children with Multichannel Cochlear Implants or Hearing Aids," *Annals of Otolaryngology and Laryngology* 104, suppl. (1995): 334-37.
 48. Harlan Lane and Ben Bahan, "Effects of Cochlear Implantation in Young Children: A Review and a Reply from a DEAF-WORLD Perspective," *Otolaryngology: Head and Neck Surgery* 119 (1998): 297-308.
 49. Harlan Lane and M. Grodin, "Ethical Issues in Cochlear Implant Surgery: An Exploration into Disease, Disability, and the Best Interests of the Child," *Kennedy Institute of Ethics Journal* 7 (1997): 231-51.
 50. United Nations, *Rights of Persons Belonging to National, or Ethnic, Religious and Linguistic Minorities*, Resolution 47/135 (New York: United Nations, 1992).
 51. Harlan Lane, "Constructions of Deafness," *Disability and Society* 10 (1995): 171-89.
 52. Claude-Henri Chouard, *Entendre sans Oreille* (Paris: Laffont, 1978).
 53. Frederick Douglass, Public Address on Independence Day, 1852, <http://www.historyplace.com/speeches/douglass.htm>.

18. Beyond Culture: Deaf Studies and the Deaf Body

DOUGLAS C. BAYNTON

THE CONCEPT OF DEAF CULTURE is fundamental to the field of Deaf Studies. In recent decades, the distinctive cultural attributes of the American Deaf community have been documented and described at length, among them a shared history, a rich literary culture, rules of etiquette and naming practices that differ from those of the larger hearing society, a strong tendency to marry within the group, a unique means of transmitting cultural knowledge between generations, and of course a complex visual language. In addition, like other cultural minority groups, Deaf people have established a variety of social, political, and economic organizations, as well as a periodical press, dating from the mid-nineteenth century. Perhaps most importantly, Deaf people share fundamental values that differ from those of the hearing Americans around them, in particular having the value of American Sign Language (ASL) and the Deaf world. The existence of a deep, rich, and long-standing culture of American Deaf people is now beyond reasonable dispute.¹

As important and useful as it has been, however, the concept of Deaf Culture increasingly appears inadequate by itself as an explanation of the Deaf community and the experiences of Deaf people. For example, recent research has shown that Deaf people process visual information differently than hearing people, and in some ways more efficiently. This has complemented a growing emphasis in recent years on the centrality of vision to Deaf experience, with some Deaf people suggesting that they instead be referred to as "Seeing people" or "Visual people."² The statement by George Veditz that Deaf people "are facing not a theory but a condition, for they are first, last, and all the time *the* people of the eye," has become a popular aphorism among Deaf activists.³ Deaf people now often speak of "deaf eyes," a characteristic and recognizable way Deaf people have of using the eyes. Under an exclusively cultural model, how do we discuss such phenomena? What, moreover, is the implication of arguing, as Deaf people long have argued, that it is in the *nature* of deaf people to use signed languages, a view that has been given support by linguistic research into language acquisition and development among deaf children? All of these suggest that Deaf people differ from hearing people in physical (or, more precisely, sensory) ways that are not explained by culture.

This is not to say that sensory difference by itself is sufficient to explain Deaf identity. For example, many people identify themselves as hearing impaired, hearing disabled, deaf, or hard of hearing who are not culturally Deaf: they do not share the values of Deaf people, they are not (or only partially) fluent in the language of the community, and