A Different Center

On June 27, 1990, the United States Food and Drug Administration approved a proposal by the Cochlear Corporation to market a "bionic ear" for surgical insertion in deaf children over the age of two. More properly called a cochlear prosthesis, this device converts sound waves into electrical currents that are delivered to a wire implanted in the child's inner ear. With the headline "New Hope for Deaf Children: Implant Gives Them Hearing and Speech," *American Health* enthused: "Results promise to be even more dramatic for very young children [than they have been for adults]. The implants will actually allow them to speak." The modern miracle of biotechnology, you say, as do the media, and yet the National Association of the Deaf has called the FDA approval "unsound scientifically, procedurally, and ethically." Audiologists and otologists—those who measure hearing and those who treat it medically, experts who "have only the best interests of deaf children at heart"—proclaim a dramatic advance; yet the American deaf community, whose members could not love deaf children more, proclaim a dangerous setback to their interests.

Cochlear implantation is a surgical procedure, lasting about three and a half hours under general anesthesia, and it requires hospitalization for two to four days. A broad crescent-shaped incision is made behind the operated ear, and the skin flap is elevated. A piece of temporalis muscle is removed. A depression is drilled in the skull and reamed to make a seat for the internal electrical coil of the cochlear implant. A section of the mastoid bone is removed to expose the middle ear cavity. Further drilling exposes the membrane of the round window on the inner ear. Observing the procedure under a microscope, the surgeon pierces the membrane. A wire about 25 millimeters long is pushed through the opening. Sometimes the way is blocked by abnormal bone growth in the inner ear; the surgeon will generally drill through this but may have to settle in the end for only partial insertion of the wire. The wire seeks its own path as it moves around and up the coiled inner ear, shaped like a snail and

called the cochlea, from the Latin for "snail." The exquisitely detailed microstructure of the inner ear is often ripped apart as the electrode weaves its way, crushing cells and perforating membranes; if there was any residual hearing in the ear, it is almost certainly destroyed. The auditory nerve itself is unlikely to be damaged, however, and the implant stimulates the auditory nerve directly. The internal coil is then sutured into place. Finally, the skin is sewn back over the coil.

Not long after the FDA gave the green light to surgeons to implant the Cochlear Corporation prosthesis in children, the manufacturer announced a promotional meeting in Boston and I attended. Two sets of satisfied parents and their implanted children were flown in for the occasion and seated center stage. "Barry," nine, had become deaf when he was six and a half; "June" was four and a half and born deaf. Both children had been using their implants for about a year, and both attended special programs for deaf children housed in ordinary public schools. Barry could understand much of what his teachers said, but June required a sign language interpreter. Both children spent several hours every day practicing listening and speaking, under their mothers' tutelage or that of therapists.

During the presentation, researchers from the Cochlear Corporation reported on their investigations with several hundred implanted children, and then the members of an implant team spoke in turn: first the surgeon, then an audiologist and a speech therapist, and finally a special educator. While the scholars held forth and the parents beside them listened attentively, I noticed the two children, half-screened from the audience behind their parents' backs, signing furiously to each other across the stage.

Will the typical deaf child, who was born deaf, like June, or who became so early in life, be able to understand ordinary conversation after undergoing the surgery and a lot of training? Probably not. Will he or she be able to speak intelligibly? Probably not. Will he learn English better than he would have without the implant? Probably not, but we do not know. Will he be able to succeed in an ordinary school with hearing children? Probably not. Will he then generally rely on vision rather than hearing? Yes.

Although the implanted deaf child will not move easily in the hearing world, it is unlikely that he will move easily in the deaf community either, unlikely that he will learn American Sign Language (ASL) fluently and make his own the fundamental values of that community. So there is a real danger that he will grow up without

any substantive communication, spoken or signed. He may develop problems of personal identity, of emotional adjustment, even of mental health—this has not been studied. You may well ask: If the benefits are so small and the psychological and social risks so great, why did the FDA approve general marketing of the device and why do surgeons implant it?

Why indeed? Why would such heroic medicine be practiced on young deaf children? For this to be justified, the plight of the deaf child must be seen as truly desperate. But surely, you say, the plight of the deaf child *is* desperate. The child is unable to communicate with his mother and father—nine out of ten deaf children have hearing parents. He will receive a "special" education —in fact an especially unsuccessful education that commonly leads to underemployment. He will take a deaf spouse and be shut off from the world of his hearing parents and the mainstream of American society.

Most people who were born deaf or became so early in life, like the child we are discussing, and who grew up deaf as part of the deaf community have a different point of view. They see themselves as fundamentally visual people, with their own visual language, social organization, history, and mores—in short, with their own way of being, their own language and culture. Scholarly research since the 1970s in such fields as linguistics, anthropology, sociology, and history supports them in this claim. Yes, the deaf child faces many obstacles in life, but the lack of communication at home, inferior education in school, discrimination in employment, are obstacles placed in his way by hearing people who, if only they came to know the deaf community, could readily remove them.

In their book on American deaf culture, deaf authors Carol Padden and Tom Humphries say that hearing professionals who work with deaf people have a different "center" than their clients, which they illustrate with this observation: From a hearing point of view, it is better to be hard of hearing than deaf; someone who is "a little hard of hearing" is much less deaf than someone who is "very hard of hearing." Deaf people see things the other way around. When they sign that an acquaintance is A-LITTLE HARD-OF-HEARING† they mean

†English glosses for the signs in American Sign language (ASL) are conventionally written in capital letters. Hyphens connect glosses that are one word in ASL. It is important to note that glosses omit most of the grammar of ASL. They are *not* translations.

that the person has some of the ways of hearing people but basically is quite deaf. When they sign that someone is VERY HARD-OF-HEARING, they mean that the person is very much like hearing people, scarcely like deaf people at all. The same opposing points of view of the hearing benefactor and the deaf beneficiary are revealed in this observation: Members of the deaf community commonly condemn a deaf acquaintance who is ORAL —that is, who does not fully acknowledge that he is deaf. They say disparagingly that that person ALWAYS-PLANS actions for every situation, in order to pass acceptably in a hearing world. Hearing experts, however, do not understand why some deaf people condemn others who are oral and trying to pass; they use terms like "afflicted" for the first group, deaf people who do not speak, and applaud the efforts of those who try to.

Two cultures, two points of view, two different "centers." This book is an exploration of the gulf that separates these two vantage points.

Hearing Representations of Deaf People

What are deaf people like? There are at least three approaches to answering the question. You may, first, reflect on the social identity of deaf people; they belong to a category, and the category has attributes that are part of our popular culture, as a result of the treatment of deaf people in literature and in the media. Second, you may make an extrapolative leap and try to imagine what your world would be like if you were deaf. Most hearing people, if they are led to think about deaf people, soon make this extrapolative leap, for they have little else to guide them; they have not read about deaf language and culture, and extrapolation must stand in for real knowledge. If it happens that you know someone who is deaf, a third way of apprehending deafness is open; it takes on the characteristics of that particular deaf person, as in: "John understands me when I talk to him directly; therefore, deaf people can lip-read."

All of these approaches commonly lead hearing people to the same point of departure in their representations of deaf people: Deafness is a bad thing. In hearing society, deafness is stigmatized.

The sociologist Erving Goffman distinguishes three kinds of

stigma: physical, characterological, and tribal. "There is only one complete, unblushing male in America," he explains. "[He is] a young, married, white, urban northern heterosexual Protestant father of college education, fully employed, of good complexion, weight, and height, and a recent record in sports." Any deviation is likely to entail a stigma, and we tend to impute many stigmas when we find a single one. All three categories of stigma are ascribed to deaf people. Physically they are judged defective; this is commonly taken to give rise to undesirable character traits, such as concreteness of thought and impulsive behavior. Hearing people may also view deaf people as clannish—even, indeed, an undesirable world apart, social deviants like those Goffman lists: prostitutes, drug addicts, delinquents, criminals, jazz musicians, bohemians, gypsies, carnival workers, hoboes, winos, show people, full-time gamblers, beach dwellers, gays, and the urban unrepentant poor. But even if the American deaf community were known for what it is, a linguistic and cultural minority with a rich and unique heritage, it would still be subject to a tribal stigma, as is, for example, the Hispanic-American community.

Stigma is relational. In the deaf community, to be called ORAL, we have seen, is unacceptable. ORAL means you have made the wrong life choices, you have uncritically embraced alien values that place a premium on speech. Hearing people fail to see what is wrong with deaf people's being ORAL; articulateness is prized in American society; gesturing is not.

In the hearing stereotype, deafness is the lack of something, not the presence of anything. Silence is emptiness. The deaf community, say Padden and Humphries, recognizes that "silent" "is part of a way of viewing deaf people that is pervasive in hearing society; they accept it and use it as an easy way for others to recognize them." Thus the magazine published by the National Association of the Deaf (NAD) was long called *The Silent Worker*. But for hearing people, "silent" represents the dark side of deaf people. They must not have the orientation and security in their environment that we have; of course, they can't appreciate music, we tell ourselves; nor can they engage in conversation, hear announcements, use the telephone. The deaf person moves about, it seems to us, encapsulated; there's a barrier between us. Hence the deaf person is isolated. Ivan Turgenev's character Gerasim, for example, was "shut off by his affliction from the society of men," as was Carson McCullers's deaf protagonist in *The Heart Is a Lonely Hunter*.

In the parlance of hearing people, ordinary deaf people can't really communicate; for them to attempt it is to engage in a *dialogue des sourds*—a deaf dialogue, meaning mutual incomprehension. Hearing people are called deaf, by metaphorical extension, when they refuse to listen, especially to moral advice. If great flourishes in English are associated with a refined mind, simple, awkward speech and gesticulation are associated with a simple mind. Because language and intellect are so linked in our representations of people (we are surprised to hear a towering intellect expressed—unless by deliberate intent—in a Southern drawl or in ungrammatical sentences), deafness seems a defect of intellect. The "dumb" of "deaf and dumb" appears to refer not only to muteness but to weakness of mind. Joanne Greenberg's deaf couple in *In This Sign* are ignorant even about childbearing. Paradoxically, in a reaction formation, deafness may also seem ennobling: the very simplicity of mind, the childlikeness, bespeaks a pure soul, one free of the artifices of civilization. Dickens's Sophy seems to have descended from heaven; Maupassant's Gargan is speechless, an ignorant shepherd, but strong, upright, pure in his misery.

In fact, we imagine two kinds of deafness. The more usual kind is linked in our minds with blue-collar jobs or even poverty. Eudora Welty's deaf couple in "The Key" are poor, naïve, "afflicted," and childlike. A deaf person may sell cards inscribed with the finger alphabet; or work in the manual trades, say as a printer. But then there is the exceptional deaf person who can speak and lip-read—who is just like you and me, except for some slight difference. (What a relief!) This person does not sell cards or labor with his hands; he is not poor or even middle-class in our imagination, but distinguished, elegant. Henry Kisor, book editor at the Chicago *Sun-Times*, confirmed this comfortable image of the deaf person in his 1990 autobiography, *What's That Pig Outdoors*. (The title was chosen to illustrate the perils of lip-reading.)

Our society is sufficiently rich and enlightened that we are prepared to sympathize with marginal people who endorse our norms but, for reasons beyond their control, cannot live up to them. The deaf actress Marlee Matlin won the admiration of many hearing people when she chose to speak aloud on national television, rather than through an interpreter, on receiving the Oscar for her role as a culturally deaf person in the film *Children of a Lesser God*. By the same act she incurred criticism from some members of the American

deaf community. For them, in those few halting words she negated the principles of the story she had so brilliantly enacted; she chose symbolically not to accept the award as a member of the deaf community; and she seemed to endorse the view that any amount of English is better for deaf people than the most eloquent American Sign Language.

Late-deafened people who make an effort to speak English and lip-read, to overcome the hurdles of their handicap, are much less discomfiting to hearing people than the members of the deaf community, with their distinctly different ways and language. What is unforgivable is that members of the deaf community insist they are fine—for example, two-thirds of deaf adults interviewed in a 1988 survey thought their social life was better than hearing people's—when in fact we can give them a thousand reasons why they can't be. Goffman points out that the stigmatized are expected to keep a bargain: "they should not test the limits of the acceptance shown them, nor make it the basis for still further demands." Thus, the person who is disabled (in our eyes) is expected to *be* disabled; to accept his role as such and to conform, *grosso modo*, to our representation of him. In return we will class him not among the bad (prostitutes, drug addicts, delinquents) but among the sick. The sick and the infirm have a claim on our tolerance and, even more, on our "reasonable accommodation," our compassion, our help.

But we've got it all wrong. Come with me to the annual convention of the Massachusetts State Association of the Deaf, for example. Friends, frequently former schoolmates, embrace at the joy of seeing each other after long separation. There's a lot of catching up to do, and throughout the hotel there are groups of deaf people conversing intently in ASL. At the same time, there are workshops in various meeting rooms to explore issues of common concern, such as the political, social, and athletic program for the year; the governance of the association; outreach to hearing parents; wise personal investing; new technology of interest to deaf people; and deaf awareness—including the roles of various deaf organizations in community service like teaching ASL or counseling unemployed deaf people. At dinner, there will be a banquet speaker—the last time I attended, it was the deaf president of Gallaudet University, the world's premier institution of higher learning in the liberal arts for deaf students. Speakers commonly urge on the audience some course of organized social action—protests at the statehouse in behalf of funding for

interpreters; activism in the schools in favor of ASL; letters to the networks to promote captioning—action to enhance the lives of deaf children and adults.

The pageant to choose Miss Deaf Massachusetts has been part of the annual convention in some years. Young women sponsored by various Massachusetts high schools (or high school programs) for deaf students are judged by a committee of deaf community notables for their knowledge of state and national deaf history, for their presentation of their background and career goals, and for the sheer delight of looking at them. The winner becomes a contestant in the national competition held during the convention of the National Association of the Deaf. It has been my pleasure to come to know Miss Deaf New Jersey of some years ago, now a colleague at my university, and Miss Deaf America of 1989, both extraordinarily keen and beautiful young women. When I left the packed auditorium where the 1989 winner was being selected, a deaf student leader hailed me and asked what I thought of the pageant. I told her I liked parts of it but felt a little uneasy at seeing young women displayed like so many pounds of beef on the hoof. "You've a lot to learn about deaf culture," she replied. "I think it's just fine!"

In the course of the state convention there may be events that the deaf clubs in towns and cities across the nation also feature traditionally: a theatrical performance, a raffle, games, a dance, a sporting match. The state convention ends with numerous awards in recognition of service to the deaf community. The master of ceremonies (the last one I recall was B. J. Wood, who directs the state Commission for the Deaf and Hard of Hearing) recounts the many achievements of each recipient, who is given a plaque and asked to say a few words—they're usually about how he (or she) could not have done it (organized a successful tournament, put on a show, conducted a fund-raiser, run the summer camp for deaf children, published the community newspaper) without the help of A, B, and C. The recognition of service and the warm congratulations all around continue for hours, until friends bid each other a reluctant good night.

So the members of the American deaf community are not characteristically isolated, or uncommunicative, or unintelligent, or childlike, or needy, or any of these things we imagine them to be. Why, then, do we think they are? This mistake arises from an extrapolative leap, an egocentric error. To imagine what deafness is like, I imagine my world without sound—a terrifying prospect, and one that con-

forms quite well with the stereotype we project onto members of the deaf community. I would be isolated, disoriented, uncommunicative, and unreceptive to communication. My ties to other people would be ruptured. I remember my parents censuring me with silence; it was bearable for four hours, and then I implored their forgiveness. I recall the "silent treatment" of offenders in the Army. The Tunisian novelist Albert Memmi, author of several sociological studies of oppression, observes in his book on dependency: "The person who refuses to communicate severs the psychological ties that connect him to the other person. In so doing he isolates the other person and can drive him to despair." A world without sound would be a world without meaning. What could be more fundamental to my sense of myself than my sensory milieu—unless it be my spoken language.

What motivates the extrapolative error in disinterested laymen is existential dread. There but for the grace of God go I. "Contact with someone afflicted with a disease is regarded as a mysterious malevolency," writes critic and author Susan Sontag. Some of my hearing friends say they are uneasy around deaf people for a different reason, because they don't know how to communicate with them; but then I ask them if they give blind people a wide berth and look away from physically handicapped people, and they acknowledge that they do.* Each meeting with a person we perceive as handicapped is an invitation to make the extrapolation—and to experience dread. They are deserving of our sympathy because we are deserving of our sympathy. Nineteenth-century authors catered to such sentiments by idealizing their deaf characters. The American poet Lydia Sigourney sang of "the silent ecstasy refined" displayed by a pupil at the first school for deaf children in America, and Alfred de Musset's beautiful deaf Camille "had admirable purity and freshness."

Mothers in one central African nation report that on discovering that their child was deaf, their first thought was to verify that their ancestors had been properly buried. Mothers in many societies consider the cause of their child's deafness to be spirit aggression. We are fragile and dependent beings, they seem to imply, and deafness can be retribution for a moral failing. So, too, American mothers experience inexplicable guilt on discovering that they have a deaf child. There is a persistent belief, Sontag notes, that illness reveals, and is a punishment for, moral laxity. It is somehow reassuring when contracting a disease like AIDS is the result of doing something "wrong"; that hemophiliacs contract it through no act of their own

arouses our rage at an immoral universe. It would be better if there were a reason for contracting deafness, something we could do, or refrain from doing, to avoid it. Such a reason might also justify our holding deaf people at arm's length, even justify our treating them badly. But there generally isn't one; so deafness or some other physical handicap may happen to us, as it were, whimsically, and that is dreadful.

The hearing person's extrapolation to what deafness must be like—a world without sound, without facile communication—is not entirely without a counterpart in the real world, for each year thousands of people lose substantial hearing because of illness, trauma, or old age. A few may take steps to enter the deaf community, to learn ASL, make friends in that community, join deaf organizations, attend a deaf club, and so on; most do not.

Growing up deaf, as have most users of ASL, is quite another matter. To evaluate that world of the deaf community, extrapolation from the hearing world is of no use at all. Is it better to be deaf or is it better to be hearing? Anthropologist Richard Shweder asks, "Is it better to have three gods and one wife or one god and three wives?" Of course, the question makes no sense except in relation to a cultural "frame." To know what it is to be a member of the deaf community is to imagine how you would think, feel, and react if you had grown up deaf, if manual language had been your main means of communication, if your eyes were the portals of your mind, if most of your friends were deaf, if you had learned that there were children who couldn't sign only after you had known dozens who could, if the people you admired were deaf, if you had struggled daily for as long as you can remember with the ignorance and uncommunicativeness of hearing people, if . . . if, in a word, you *were* deaf.

The extrapolative error is an error twice over: True representations of the members of another culture cannot be had without a change in frame of reference, which requires, at least, understanding and empathy. It is naïve to imagine otherwise, and it is self-defeating. There will be no successful relations between hearing and deaf people, no successful education of deaf children, until the extrapolative error is set aside.

The Infirmity and Cultural Models of Deaf People

The first time I saw ASL—really looked at it—was in 1973 at the Salk Institute for Biological Studies in La Jolla, California. On the sunlight-splashed terraces overlooking the Pacific, amid eucalyptus groves, a man and a woman were engaged in rapt silent conversation, their hands flying, their faces projecting fleetingly a hundred human emotions. Although I was in La Jolla as visiting professor of linguistics at the University of California, my first assumptions about this scene were quite wrong. I thought the couple must be deaf and their hand movements some sort of mime. Dr. Ursula Bellugi, who directs the Salk Institute's Laboratory for Cognitive Neuroscience, set me straight: The man was a hearing linguist who had learned ASL as an adult, the woman was deaf, and I was witnessing a natural language, one that was quite unlike English, although it had features that could be found in various spoken languages around the world. In one way it was different from all oral languages, for it was manual and visual; and in one way it was like all of them, for it had rules for combining elements into words and rules for combining words in sentences—a grammar.

It is hard to explain to a nonlinguist my emotion: I felt as Balboa must have felt on first seeing the Pacific! Language could be expressed, it appeared, by movements of the hands and face just as well as by the small, sound-generating movements of the throat and mouth. Then the first criterion for language that I had learned as a student—it is spoken and heard—was wrong; and, more important, language did not depend on our ability to speak and hear but must be a more abstract capacity of the brain. It was the brain that had language, and if that capacity was blocked in one channel, it would emerge through another.

Linguistic research on ASL, which began in the 1960s with the work of William Stokoe and colleagues at Gallaudet University, mushroomed in the following decades and soon led to research describing the sign languages of other deaf communities—in Britain, Sweden, France, China, and Thailand, to mention a few examples. As many speakers of oral languages are aware, spoken words are made up of

a small inventory of vowels and consonants strung out in a row according to rules. Signs, it turns out, also consist of a small inventory of elements—handshapes, their locations on or near the body, their orientations, and their movements. These components of signs occur simultaneously. Using a fully spread hand, touch your thumb to the side of your forehead twice—that's the ASL sign for FATHER. Repeat the sign but with your thumb touching your breast and you get FINE in ASL. Repeat the sign for father but replace the two taps with an arcing movement away from your forehead; that's GRANDFATHER. Put the spread handshape on both hands facing out in front of your waist, cup your hands a little, and wiggle your wrists; that two-handed sign means TO-CHAT-IN-SIGN.

Just as there are rules in English that restrict the allowable sequences of vowels and consonants (e.g., if a word begins with three consonant sounds, the first must be *s*), so there are rules that restrict the simultaneous combinations of the four elements of signs—and apparently for the same reasons: simplicity of execution and of perception. One such rule in the structure of ASL requires that if both hands are moving in a sign, then the handshapes, locations, and movements of the two hands must be the same. To illustrate, sign BICYCLE; close both hands into fists and move them in alternating circular movements in front of your chest. If the two hands in a sign have *different* handshapes, then one must be stationary and, furthermore, only six of the score of allowable handshapes in ASL are permitted on that stationary hand. An example is DISCUSS, where an extended index finger strikes an open palm.

In a classic experiment, Dr. Bellugi and linguist Susan Fischer had hearing children of deaf parents, who were fluent in both English and ASL, tell the same story in each of the two languages. Since it requires much more time to move the large limbs of the body than the small articulators of the mouth, you might expect that signs will take longer to articulate than words, and that therefore a story will be longer in sign than a corresponding spoken one. You would be only half right; signs do take longer than words, but in Bellugi's and Fischer's experiment the two versions of the same story generally lasted about the same amount of time. The reasons for this bring us to the heart of the differences between signed languages and spoken ones, and between ASL and English in particular.

Signed languages exist in space and naturally take advantage of spatial reasoning to convey messages. In ASL, for example, I-SHOW-

YOU is one sign moving outward from the signer; YOU-SHOW-ME moves inward toward the signer. Where English would require three words in each case, there is only one sign with its incorporated movement. If I sign MY BROTHER and point to the left and MY SISTER and point to the right, "My brother met my sister" can be rendered by a single sign moving from left to right. I can then attribute qualities unambiguously to my brother or my sister by making the signed attributions either to the left or to the right. Many ASL verbs, such as GIVE, NAME, PREACH, SAY-NO, ASK, HATE, MOCK, are executed with movements that incorporate who is doing the action to whom. Since that information is in the modified sign itself, ASL, like many spoken languages, such as Russian, does not have to restrict word order, as English does. For example, the three signs HORSE, COW, and KICK (or the equivalent words in Russian) might be arranged in any order in ASL (or Russian), and there would still be no doubt about which animal was kicking which. Word order is available, therefore, to serve other purposes; thus, it is common for an ASL sentence to put the topic first and then the comment, as in the sentence with two signs: GIVE-HIM-THE-BOOK, I-DON'T-WANT-TO.

Changes in the movement of the sign also convey information about time that requires adding adverbs in English, such as "frequently," "repeatedly," "over a long time." Thus, SICK and SICK-FOR-A-LONG-TIME-OVER-AND-OVER-AGAIN (repeated lengthy bouts of illness) are each one sign. Movements meaning "to each of them," "to selected ones at different times," "to any and all at different times," are imposed on sets of verbs to give single complex signs, such as PREACH-TO-SELECTED-ONES-AT-DIFFERENT-TIMES. Changes in the shape of the sign can incorporate information; thus the sign DAY can be made into TODAY, the sign GIVE into GIVE-A-BOOK. Movement can also convey grammatical categories; where English would add a suffix to the word to indicate that it is a noun or verb, ASL uses tense or relaxed movement and repetition.

This brief description of a little of the grammar of ASL, based on the work of Dr. Bellugi and colleagues at the Salk Institute, may make it clear how stories told in ASL can reach the same rate of propositions as stories told in English—about a proposition every second and a half. English words are, on the average, twice as fast to articulate as signs in ASL, but it takes many more English words and word endings than it takes ASL signs to say the same thing. To convey the logical relationships in a sentence, as any language must do, ASL incorpo-

rates the information into its signs; they are layered and richly configured, as appropriate to the sense of vision. English, on the other hand, accomplishes the same ends by stringing many words and word endings out in a row. This is a strategy more suited to a spoken language than a visual one. Hence, the two languages clearly bear the impress of their different modalities, visual and auditory, and are very different languages indeed.

The literature of American deaf culture, told in ASL, consists of history, stories, tall tales, legends, fables, anecdotes, poetry, plays, jokes, naming rituals, sign play, and much more. Since the literature of the American deaf community recounts the deaf experience, much of it concerns, directly or indirectly, hearing oppression of deaf people. For example, in its performance of the play *My Third Eye*, the National Theater of the Deaf calls attention to some of the more laughable features of hearing people's behavior: our endless conversations on the telephone, our acute fear of being touched, our visual inattentiveness, our frigid faces, where only the jaw moves, faces that deny by their impassivity what our words declare.

Mastery of ASL and skillful storytelling are highly valued in deaf culture. There are success stories, in which the deaf person triumphs over adverse conditions—bluffing one's way into a job with the help of deaf accomplices, for example. There are also stories about starting a deaf club, buying a clubhouse, beating the other team. There are stories about the material culture of the deaf community—grandfather clocks rigged with weights that fall at the appointed hour and awaken the deaf owners with their vibrations—and tall tales (the weights waken all the deaf people in the town). Storytelling develops early in residential schools for deaf children, where youngsters recount in ASL the plots of cartoons, Westerns, and war movies, and the idiosyncratic mannerisms of hearing teachers. There is also formal storytelling, for example, bearing witness to the acts and character of great deaf figures. Clear communication is highly valued; stories should be rich in detail, start at the beginning and end at the end, and contain plain talk; hinting and vague talk in an effort to be polite are inappropriate and even offensive. As might be expected, members of this culture have quite distinct rules for attention-getting, turn-taking, polite discourse, name-giving, and other behaviors related to language.

Through ASL literature, one generation passes on to the next its wisdom, its values, and its pride, and thus reinforces the bonds that

unite the younger generation. Since ASL is not a written language, publications in English—newspapers, magazines, and books written by and for deaf people—have played an important role historically in the bonding of American deaf culture. Another striking feature of this culture is its high rate of endogamous marriage: An estimated nine out of ten members of the American deaf community marry other members of their cultural group. Particularly important cultural institutions, the sites of much cultural transmission, have been the network of residential schools and the numerous deaf clubs throughout the nation. Deaf athletic, political, religious, and fraternal organizations also play an important role.

What are some of the salient values of this culture? Residential school ties are exceedingly important, and graduates are likely to return frequently for alumni events. When asked where they are from, deaf people will often reply with the name of the residential school they attended; it invariably comes up in introductions. Interviewed at a deaf club, an octogenarian eloquently testified to the importance of school ties: "You see those people sitting over there? Those are my classmates from the Berkeley School. When I was nine, my mother took me out of hearing boarding school and put me in the institution. They all befriended me, and we have been tight ever since. Of course, once we all started families, we didn't always see each other as regularly as we do now that everyone is retired. It's hard on my husband; he's from out of state and didn't grow up with us, so he feels kind of left out."

Deaf identity itself is highly valued; deaf people seem to agree that a hearing person can never fully acquire that identity and become a full-fledged member of the deaf community. Even with deaf parents and a native command of ASL, the hearing person will have missed the experience of growing up deaf, including attending a deaf school, and is likely to have divided allegiances. Speech and thinking like a hearing person are negatively valued in deaf culture. Deaf people who adopt hearing values and look down on other deaf people are regarded as traitors. "We are all in the same family," said one deaf leader, and, indeed, the metaphor of family is fundamental and recurrent. It is by hearing standards a heterogeneous family: the salience of deaf identity overshadows differences of age, class, sex, and ethnicity that would be more prominent in hearing society. Likewise, there is a penchant for group decision-making, and mutual aid and reciprocity figure importantly in deaf culture. Favors are more

easily requested, my deaf friends tell me, more readily granted, and there is less individual accounting than in American hearing society. From a hearing person's perspective, this "family" engages in a great deal of hugging. Deaf people frequently hug on meeting and invariably hug on parting—real hugs! They mock the ritual hugs that hearing friends sometimes engage in. Partings can take a very long time and proceed in stages. Abrupt departures and even temporary unexplained departures are unacceptable.

There is fierce group loyalty, and this may extend to protectively withholding from hearing people information about the community's language and culture. Members of the deaf community believe, as do members of other cultural minorities, that one should marry within one's minority: marriage with a hearing person is definitely frowned upon. The deaf community collectively values deaf children highly; deaf adults in rural areas, for example, will drive great distances to see deaf children, especially if the children might otherwise lack such contact.

Clearly, we are concerned here with a language minority; a community that consequently has a rich culture and art forms of its own, a minority history and social structure. What is in dispute intellectually is the use of one type of description rather than another for this language minority, a cultural description rather than one based on infirmity. What is in dispute pragmatically is power and money.

To apply an infirmity model to members of a group is to regard them and interact with them particularly with respect to our cultural conception of bodily defect. This conceptual framework, which one normally acquires in the course of acculturation, is implicit; it entails issues, values, and reference to societal institutions. Some of the issues that naturally arise when a certain way of being or behaving is construed as an infirmity are: By what criteria and by whom is this construed as an infirmity; how did the infirmity arise; what are the risks and benefits of the available treatments, if any; what can be done to minimize the disabling effects of the infirmity? The values invoked are largely negative; we may admire someone's accommodation to his infirmity or his courage in struggling with it, but the infirmity itself is generally considered undesirable; at best we are ambivalent. The institutions that are part of this conceptual framework include notably the biological sciences and the health and social welfare professions.

To apply a cultural model to a group is to invoke quite a different

conceptual framework. Implicit in this posture are issues such as: What are the interdependent values, mores, art forms, traditions, organizations, and language that characterize this culture? How is it influenced by the physical and social environment in which it is embedded? Such questions are, in principle, value neutral, although of course some people are ill-disposed to cultural diversity, while others prize it. The institutions invoked by a cultural model of a group include the social sciences; professions in a mediating role between cultures, such as simultaneous interpretation; and the schools, an important locus of cultural transmission.

I maintain that the vocabulary and conceptual framework our society has customarily used with regard to deaf people, based as it is on infirmity, serves us and the members of the deaf community less well than a vocabulary and framework of cultural relativity. I want to replace the normativeness of medicine with the curiosity of ethnography.

The contrast between deafness-as-disability and deafness-as-culture is sharpened when we consider the views of leaders of the disability rights movement in the United States and Great Britain. Those leaders and some scholars in the field of disability have presented a persuasive case that people with physical and mental disabilities are oppressed. They reject the "personal tragedy" view of disability and point to the ways in which society has discriminated against people with disabilities in education, in the employment market, and in physical access to public facilities. Indeed, they argue, society creates the conditions that lead to much of disability in the first place, such as war and poverty, and society determines to an important degree who shall be categorized as disabled and who not. For example, earlier in this century, educational psychologist Henry Goddard, using the new tests of IQ, "discovered" morons and announced that a new and dangerous form of disability, rampant among the poor and requiring custodial care, was in our midst. When it comes to mild mental retardation, the evidence is compelling that society has a large role in determining who is disabled and who is not.* In 1984, the U.S. Court of Appeals affirmed a finding that California's use of IQ tests to classify black children as mentally retarded discriminated against them intentionally on the basis of race.

According to disability theorist Paul Abberley, the view of disability as oppression rests on two fundamental assertions: first, that disability is in part a historical product of social forces, not merely a biological

necessity; and second, that the disabled mode of living has value in its own right, even as we condemn the conditions that gave rise to the impairment. Consider people with physical handicaps, for example: They affirm that the design of the environment often disables them; in better-designed environments they are disabled less, or not at all. And they ask that their particular way of being and of living be respected and valued, even while we regret the lack of good medical care, or industrial safety, or the war that led to their disability. This model seems to apply to a wide range of disabilities, including hearing loss from aging, accident, or illness. It does not apply to members of deaf communities.

True, members of the American deaf community, like Americans with disabilities, African-Americans, and Hispanic-Americans, among others, are disadvantaged by the beliefs and practices of the majority in the United States. But the ambivalence called for in the case of disabilities—respecting that unique organization of life while regretting the conditions that create it—is not appropriate in the case of deaf culture. Deaf parents' joy at the birth of a son or a daughter is not commonly diminished by their finding that the child is deaf. The experience of the "Hanleys" is typical: Mrs. Hanley sat by the window on the Fourth of July, she recounts, watching children set off fireworks while her baby slept undisturbed. "I thought to myself, 'She must be deaf.' I wasn't disappointed; I thought, 'It will be all right. We are both deaf, so we will know what to do.' " Joan Philip Meehan comes from a large deaf family, all of whom had hoped that her baby would be born deaf. "I want my daughter to be like me, to be deaf," she affirmed in an interview with the Boston *Globe*. In the words of British deaf leader Paddy Ladd: "The deaf community regards the birth of each and every deaf child as a precious gift." American experts expressed the same view in a 1991 report to the National Institutes of Health; research in genetics to improve deaf people's quality of life is certainly important, they said, but must not become, in the hands of hearing people, research on ways of reducing the deaf minority.

What makes the American deaf community more like Hispanic-Americans than disabled Americans is, of course, its culture, including its language. Membership in the deaf community is not decided by diagnosis; in fact, it is not decided at all, any more than membership in the Hispanic community. Various culturally determined behaviors, and foremost among them language, reveal whether an individual

belongs to a language minority or not. Each disadvantaged group has its unique characteristics, as well as features in common with other such groups. Women, gays, Americans with disabilities, and, arguably, African-Americans are not linguistic minorities, as are Hispanic-Americans, Native Americans, and members of the American deaf community. Gays and members of the American deaf community, on the other hand, have in common that most members of the minority do not share their minority identity with their parents and cannot develop it at home. The residential schools for deaf children provided a vital link in the transmission of deaf culture and language, which is why the deaf community finds abhorrent the dismantling of the residential schools, while the disability lobby finds abhorrent segregated schooling of disabled children in special residential schools. If a child's language and identity are bound up with mainstream American culture and that child can thrive in the local school, it is hard to see why he should not be enrolled there. This includes some partially hearing children. But nine out of ten deaf children are, or shortly will be, members of the American deaf community. They have a unique birthright and will require some measure of grouping in order to enjoy the benefits of that patrimony. That is why the grouping of deaf children and adults has always been voluntary, while the segregation of children and adults with disabilities was generally involuntary.

Anthropologist Roy D'Andrade observes that significant cultural concepts, like marriage, money, theft, are not givens but require the adherence of a group to a "constitutive rule." Different cultures have different constitutive rules. Debates about abortion (at what age is a fetus a person?), about what age defines a minor, and the like are debates about constitutive rules—they can be pursued only within a given cultural frame. "Smart" is such a concept; so are "on time," "successful," and "disability." Because there is a deaf community with its own language and culture, there is a cultural frame in which to be deaf is not to be disabled; quite the contrary, it is, as we have seen, an asset in deaf culture to be deaf in behavior, values, knowledge, and fluency in ASL. If we respect the right of people in other cultures, including those within our borders, to have their own constitutive rules, which may differ from ours (and we can refuse to do so only at the risk of being impossibly naïve), then we must recognize that the deafness of which I speak is not a disability but rather a different way of being.

Some deaf leaders will say that by insisting on the distinction between members of the deaf community and members of the hearing community who have a hearing disability, I am serving the interests of those who would "divide and conquer." It is true that by allying with other groups, the deaf community can make gains difficult to achieve on its own. But to embrace the representation of the members of the deaf community as infirm is to endorse the very principle of oppression the community has so long struggled to overthrow; it is to undermine the community's efforts in behalf of some of its most cherished goals, such as bilingual and bicultural education; it is to render inexplicable the joy that deaf adults and their hearing friends experience when they see a deaf child signing; and it is to go against the common sense of most members of American deaf culture, who are simply baffled when told they are disabled. The Massachusetts *Deaf Community News*, for example, reporting on the 1991 Americans with Disabilities Act, had to explain to its readers: "Deaf people are defined as 'disabled' for purposes of the ADA."*

We have come to look at deaf people in a certain way, to use a certain vocabulary of infirmity, and this practice is so widespread among hearing people, has gone on for so long, and is so legitimized by the medical and paramedical professions that we imagine we are accurately describing attributes of deaf people rather than choosing to talk about them in a certain way. If we but consult history or deaf people for five minutes, however, we will be reminded of the error of this "common sense" position.* There was a time in American history (as in European history) when hearing people viewed culturally deaf people predominantly in terms of a cultural model. It went without saying at that time—the better part of the last century—that you needed to know the language of the deaf community to teach deaf children, that deaf adults and deaf culture must play a prominent role in the education of this minority. Deaf people published newspapers and books and held meetings that were focally concerned with the deaf community, and they discussed the pros and cons of having their own land, where deaf people would live and govern themselves, perhaps some land grant from the federal government in the newly settled West. There were proportionately many more late-deafened children then, and it seemed a pity not to maintain their skill in speaking English, so those children who could profit from it were given an hour or so of speech training after school a few times a week. There were no special educators; the requisites of

a good teacher were a good education and fluency in ASL; nearly half of all teachers were deaf themselves. There were no audiologists, or rehabilitation counselors, or school psychologists, and for the most part, none apparently were needed. The deaf child was not "formulated, sprawling on a pin," by those professions: so many decibels of hearing loss at such and such frequencies; a profile on the Minnesota Multiphasic Personality Inventory; an IQ score. Instead, deaf children and adults were described in cultural terms: Where did they go to school; who were their deaf relatives, if any, and deaf friends; who was their deaf spouse; where did they work; what deaf sports teams and deaf organizations did they belong to; what service did they render to the deaf community?

We discover a similar conceptual framework if we consult the deaf community today. But, remarkably, those professing to serve deaf people do not consult the deaf community—remarkably because the values of our larger society demand that hearing and deaf people arrive freely at agreement on how to accomplish common purposes and, furthermore, that the overriding common purpose of all of us, hearing and deaf, should be, to use philosopher Richard Rorty's terms, "to let everybody have a chance at self-creating to the best of his or her abilities." Thus, deaf people themselves should be crucial participants in the discussion and agreement concerning the lives of deaf children and adults and the roles of the professions that serve them, but they have been excluded—socially, by law, and by oppressive education. They are excluded by statute or connivance from educating most deaf children. Their counsel, which the parent of a newborn deaf child needs more than any other, is excluded from the home and the clinic. Their services as a language model for the deaf child are eschewed and the responsibility unconscionably given to the child's hearing mother, who cannot fulfill it. Indeed, their very existence is all but denied. They are not participants in the programs of research on deaf people funded by our government annually at a cost of millions of dollars; they are merely the passive objects of that research. Their role in programs that provide services to deaf people is severely restricted.

How does the medicalization of deaf people take place? How is an infirmity model of deaf people promulgated when it is grossly inappropriate? Let us shift the focus from the person labeled infirm and his or her etiology to the social context in which the infirmity label was acquired.

If we ask culturally deaf adults how they first acquired the label "handicapped, disabled, impaired," we commonly learn that some circumstance of heredity, of birth, or of early childhood marked the child as different from its parents and created an initial breakdown in communication between parent and child. The parents then saw this as deviant relative to their norms and took the child to the experts—the pediatrician, the otologist, the audiologist. It was they who legitimated the infirmity model. Why do they do it? Because that is precisely a core function of their profession: to diagnose infirmity.

How do the experts medicalize the child's difference into deviance? First, they characterize the difference in great biological detail and often only in stigmatizing ways. Much will be said about impairment of spoken language, little may be said about acquisition of ASL. Much will be said about hearing loss, nothing about gains in visual perception and thought.* Second, while pursuing the infirmity model, the experts commonly remain silent about the cultural model; they may not even mention the community of adults who were once children much like their client. Otologists and audiologists are often poorly informed about the deaf community and its language; that knowledge is not a required part of their training. Moreover, the audiologist works for a clinic under the jurisdiction of an ear doctor. At the 1991 meeting convened in Boston by the Cochlear Corporation to promote childhood implants, a deaf leader asked an otologist at the rostrum whether his implant team informed parents, whose deaf children were candidates for surgery, about the deaf community and ASL as alternatives to implantation. The otologist replied with admirable candor: "We tend to present things from our point of view." The parents meanwhile are in crisis and unlikely to be critical of that view. If the professional person does describe the deaf community, it may well be in terms that are so concise that the parents do not really grasp an alternative conception of their child's status and destiny. The professional expert and the parents generally share the same hearing culture; they tend to evaluate and label the deaf child from that perspective.

The labeling is a prelude to profound, life-changing events, to special practices at home, to a "special" education, to training in some skills and not others, to studying some subjects and not others, to specific patterns of social relations, to the wearing of technological stigmata (electronic devices and wires), possibly to surgery, to the development of a certain self-image as a consequence of all these

forces; naturally, the labeling has its own "ritual of power." The child is seated, wearing earphones, in a small steel room. The audiologist inspects and directs him through a large glass window. A test is about to begin. One wants to succeed on tests; but the child knows that this is a test not relating to what he is best at, or capable of, but precisely concerning what he is incapable of, an alien field. The audiologist gives instructions to the child in the soundproof room: Raise your hand when you hear a sound. The child tries to obey, all the while knowing that at any moment he may be in the process of failing; there may have been a sound—of course you don't know what you haven't heard. At the end, grave pronouncements are made: According to the child's response to certain pure tones at certain frequencies and intensities, he is declared "profoundly" hearing-impaired, or "severely" so; a small percent are assigned other labels, and there are numeric cutoffs for each category. What is important is the quantification, the process, the sentencing—it has little predictive or practical value; neither "totally" nor "profoundly" nor "severely" deaf children can understand normal speech, even with powerful hearing aids. Much as another ceremony of sentencing, that of the courtroom, it exists largely to perpetuate a certain social order.*

Having measured and labeled him, the audiologist passes the healthy deaf-child-become-patient to the special educator; the child is now tagged with an infirmity model and has acquired a second persona, the one described in the accompanying dossier. The job of the educator is not to educate; it is to find an educational treatment for what the otologist and audiologist could not treat, the child's failure to acquire English normally. A difference has been identified; now a massive campaign begins to eradicate it.

The medicalization of the deaf community is marked by a long history of struggle between deaf people and the hearing people who profess to serve them, for the right to define a problem and to locate it within one social domain rather than another—to construe it as a problem of medicine, education, rehabilitation, religion, politics—is won by struggle. Toward the end of the last century, hearing teachers seized control of schools for deaf children and banished ASL and deaf teachers. With the cultural frame changed, the deaf pupil was now an outsider. Spoken language in the classroom and speech therapy failed to make him an insider, while it drove out all education, confirming that the child was defective. Unsuccessful education of

deaf children reinforced the need for special education, for experts in counseling of the deaf and in rehabilitation of the deaf. Finally and most devastatingly, deaf children in America, starting in the late 1970s, were increasingly placed in local hearing schools. Having cut off the deaf child from his deaf world, having blocked his communication with parents, peers, and teachers, the experts have disabled the deaf child as never before in American history. The typical deaf child, born deaf or deafened before learning English, is utterly at a loss as he sits on the deaf bench in the hearing classroom.* What is the teacher saying? How can I make my own thoughts clear to her? What can I do to be accepted by the other children? Is there someone here who could explain things to me after school? The infirmity model has become more plausible applied to the young deaf child; with academic integration, the medicalization of cultural deafness gained major ground while the technological "miracle" of childhood cochlear implants evolved. This latest development illustrates a principle of oppression articulated by Jean-Paul Sartre: "Oppressors produce and maintain by force the evils which, in their eyes, render the oppressed more and more like what he should be to deserve his fate."

Modernity seems frequently to be the enemy of deaf people and their community. The movement, late in the last century, to banish the traditional signed languages of deaf communities in favor of the national spoken languages was created by hearing teachers (who commonly knew no manual language) as a "modern" initiative. It was also consistent with efforts to forge linguistic and cultural unity, particularly in the new nation-states. The professionalization of teaching deaf children in this century was a "modern" development—but one that largely excluded deaf adults. Modern psychological measurement, called psychometrics, has been grievously misapplied to deaf children and adults, as I shall show. The modern invention of the telephone placed deaf people at a disadvantage; the hearing aid and the audiometer, while invaluable for hearing people with hearing losses, have arguably proved of little or no value for members of the deaf community. For deaf people, silent movies were better than the modern "talkies." Of course, with modernity imposed, some inventions mitigate the harm of others; teletypewriters used by deaf people and the captioning of television and movies are two examples. But the newest high technology concerning hearing also poses the greatest threat to the welfare of the deaf community; I mean that same technological "miracle": the microsurgical insertion of electrodes in the deaf child's inner ear.

"The best way to cause people long-lasting pain," Richard Rorty writes, "is to humiliate them by making the things that seemed most important to them look futile, obsolete, and powerless." What is most important to deaf people?

- *Their dignity* as deaf people, who, more fully than hearing people, operate in a visual-spatial world—their unique identity. Otologists and audiologists affirm that identity to be an illness and conduct heroic surgery on deaf children in a futile effort to change it.
- *Their language.* Hearing educators mangle it, attempting to make it express English on the hands, or they refuse to use it at all; they deny its standing as a natural language.
- *Their history*, which hearing people stole from them. Much as Abraham Lincoln was long presented as the leading figure in African-American history, such mention of history as occasionally occurred in textbooks for teachers of deaf students extolled hearing teachers of deaf children, such as Thomas Gallaudet. But deaf history is almost never taught to deaf children, for that would be a step toward legitimating a cultural model of the deaf way of being; deaf adults learn their cultural history today with surprise and delight.
- *Their social organization and mores*, which education and medicine declare inappropriate and obsolete.
- *Their political agenda.* But hearing experts continue to disempower deaf leaders in many of the areas most important to them.

A French deaf couple describe their disempowerment and humiliation:

> We were born deaf. We have been married ten years. We work like hearing people, live in a hearing neighborhood, drive our car like hearing people and take our vacations in the same places they do. The only difference in our lives is that we are deaf. Our two children, five and seven, were born hearing. Since their birth, their mother tongue is sign. Long before they could use words they spoke with us in our language. From their earliest childhood we made an effort to put them in touch with as many hearing people as possible, because we knew that the hearing world would be theirs one day. Now they are bilingual. Why don't hearing parents do the same thing when they have a deaf child? Why not teach them sign? Why not help them meet deaf people since it is the world they are destined to live in? When we were children, our parents prohibited our using sign. Because

> the doctors, the professors, the deafness specialists, told them to do that. Throughout all our studies, we were taught speech and lip-reading and hearing culture. But when we started our jobs, we realized that it was all a failure: as far as hearing people were concerned, we had always been and were deaf. They said we were hard to understand and that we didn't understand them. It was hard, humiliating. . . . Other deaf children should never live through the mutilating experience we have been through.

Yes, we have humiliated, we continue to humiliate, deaf people. But deaf people are "us." We need to recognize our common susceptibility to humiliation. Each time the powers-that-be succeed in applying the infirmity model to any one cultural and language minority, all such minorities are in greater danger. If members of the deaf community can be declared defective and treated accordingly, it is that much easier to do the same to African-Americans, gays, Jews. Perhaps the reader himself or herself runs a risk. Unless, of course, you are Goffman's one complete unblushing male.