

## Ethnicity, Ethics, and the Deaf-World

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This article is concerned with ethical aspects of the relations between language minorities using signed languages (called the Deaf-World) and the larger societies that engulf them. The article aims to show that such minorities have the properties of ethnic groups, and that an unsuitable construction of the Deaf-World as a disability group has led to programs of the majority that discourage Deaf children from acquiring the language and culture of the Deaf-World and that aim to reduce the number of Deaf births—programs that are unethical from an ethnic group perspective. Four reasons not to construe the Deaf-World as a disability group are advanced: Deaf people themselves do not believe they have a disability; the disability construction brings with it needless medical and surgical risks for the Deaf child; it also endangers the future of the Deaf-World; finally, the disability construction brings bad solutions to real problems because it is predicated on a misunderstanding.

It has become widely known that there is a Deaf-World in the United States, as in other nations, citizens whose primary language is American Sign Language (ASL) and who identify as members of that minority culture. The size of the population is not known, but estimates generally range from half a million to a million members (Schein, 1989). The English terms *deaf* and *hearing impaired* are commonly used to designate a much larger and more heterogeneous group than

the members of the Deaf-World. Most of the 20 million Americans (Binnie, 1994) who are in this larger group had conventional schooling and became deaf after acculturation to hearing society; they communicate primarily in English or one of the spoken minority languages; they generally do not have Deaf spouses; they do not identify themselves as members of the Deaf-World or use its language, participate in its organizations, profess its values, or behave in accord with its mores; rather, they consider themselves hearing people with a disability. Something similar is true of most nations: There is a Deaf-World, a relatively small group of visual people (Bahan, 2004; Padden & Humphries, 1988) who use a natural visual-gestural language and who are often confused with the larger group who view themselves as hearing impaired and use a spoken language in its spoken or written form. To acknowledge this contrast, often signaled in the scholarly literature by capital-D *Deaf* versus small-d *deaf*, is not to deny that there is a gray area between the two; for example, some hard-of-hearing people are active in the American Deaf-World; others are not. Oral deaf adults and late-deafened adults usually consider that they have a hearing impairment and do not self-identify as members of the Deaf-World.

This article is concerned exclusively with the smaller group, the Deaf-World. It aims to show that the Deaf-World qualifies as an ethnic group, and that an unsuitable construction of the Deaf-World as a disability group has led to programs of the majority that aim to discourage Deaf children from participating in the

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**Table 1** Properties of ethnic groups: Distinct

Collective name	Customs
Feeling of community	Social structure
Norms for behavior	Language
Values	Art forms
Knowledge	History
Kinship	

Deaf-World (programs such as oral education and cochlear implant surgery) and that aim to reduce the number of Deaf births, programs that are unethical from an ethnic group perspective. In other words, this article makes the case that our ethical standards for the majority's treatment of Deaf people depend, not surprisingly, on whether our representation of the Deaf-World is that of a disability group on the one hand or an ethnic group on the other.

### The Deaf-World Is an Ethnic Group

#### Internal Properties

Table 1 shows the criteria that have been advanced by social scientists for characterizing a social group as an ethnic group.

#### Collective Name

The members of this group have a collective name in their manual-visual language by which they refer to themselves. We refer to them by that name in adopting the English gloss of their compound sign: the *Deaf-World*.

#### Feeling of Community

Self-recognition, and recognition by others, is a central feature of ethnicity (Barth, 1969; A. D. Smith, 1986). Americans in the Deaf-World do indeed feel a strong identification with that world and show great loyalty to it. This is not surprising: The Deaf-World offers many Deaf Americans what they could not find at home: easy communication, a positive identity, a surrogate family. The Deaf-World has the highest rate of endogamous marriages of any ethnic group—an estimated 90% (Schein, 1989).

#### Norms for Behavior

In Deaf culture, there are norms for relating to the Deaf-World: for decision making, consensus is the rule, not individual initiative; for managing information; for constructing discourse; for gaining status; for managing indebtedness; and many more such rules. Cultural rules are not honored all the time by everyone any more than are linguistic rules. Such rules tell what you must know as a member of a particular linguistic and cultural group; what one actually does or says depends on a host of intervening factors, including other rules that have priority.

#### Distinct Values

The underlying values of an ethnic group can often be inferred from cultural norms. A value that appears to be fundamental in the Deaf-World is allegiance to the culture, which is expressed in prizing one's relation to the Deaf-World, in endogamous marriage, in gaining status by enhancing the group and acknowledging its contributions, in the giving of culturally related names, in consensual decision making, in defining oneself in relation to the culture, in distributed indebtedness, in the priority given to evidence that arises from experience as a member of the culture, in treasuring the language of the Deaf-World, and in promoting among Deaf people dissemination of culturally salient information (cf., Lane, 2004a; Mindess, 1999; T. Smith, 1997).

#### Knowledge

Deaf people have culture-specific knowledge, such as who their leaders are (and their characteristics); the concerns of rank-and-file members of the Deaf-World; important events in Deaf history; how to manage trying situations with hearing people. Knowing when and with whom to use ASL and when to use English-marked varieties of sign language is an important part of being recognized as Deaf (Johnson & Erting, 1989).

#### Customs

The Deaf-World has its own ways of doing introductions and departures, of taking turns in a conversation,

of speaking frankly and of speaking politely; it has its own taboos.

### Social Structure

There are numerous organizations in the American Deaf-World: athletic, social, political, literary, religious, fraternal, and many more (Lane, Hoffmeister, & Bahan, 1996). As with many ethnic minorities, there are charismatic leaders who are felt to embody the unique characteristics of the whole ethnic group (A. D. Smith, 1986).

### Language

“The mother tongue is an aspect of the soul of a people. It is their achievement par excellence. Language is the surest way for individuals to safeguard or recover the authenticity they inherited from their ancestors as well as to hand it on to generations yet unborn” (Fishman, 1989, p. 276). Competence in ASL is a hallmark of Deaf ethnicity in the United States and some other parts of North America. A language not based on sound is the primary element that sharply demarcates the Deaf-World from the engulfing hearing society.

### The Arts

First, the language arts: ASL narratives, storytelling, oratory, humor, tall tales, word play, pantomime, and poetry. Theatre arts and the visual arts also address Deaf culture and experience.

### History

Ethnic groups construct rootedness, with forms of expression that include history, territory, and genealogy. The Deaf-World has a rich history recounted in stories, books, films, and the like. Members of the Deaf-World have a particular interest in their history for “[T]he past is a resource in the collective quest for meaning [and ethnic identity]” (Nagel, 1994, p. 163). A sense of common history unites successive generations (Fishman, 1982, 1989; A. D. Smith, 1986).

### Kinship

Many ethnic groups have a belief in the land of their ancestors. However, “territory is relevant not because

it is actually possessed but because of an alleged and felt connection. The land of dreams is far more significant than any actual terrain” (A. D. Smith, 1986, p. 34). Land that the Deaf-World in the United States has traditionally felt an attachment to includes the residential schools; Deaf travel is often planned around visits to some of those schools. There is a Deaf utopian vision of “a land of our own” expressed in folk tales, novels, journalism, theater, and political discussions (Bullard, 1986; Lane, 1984; Levesque, 1994; Van Cleve & Crouch, 1989; Winzer, 1986). Deaf-Worlds are to be found around the globe, and when Deaf members from two different cultures meet, they feel a strong bond although they share no common territory and are limited in their ability to communicate with one another. In this, they are like Diaspora groups, such as the Jews. And, like the Diaspora ethnic minorities worldwide, prejudice and discrimination in the host society encourage them to cultivate their ethnicity to maintain their dignity despite social marginalization.

Some scholars maintain that the core of ethnicity lies in the cultural properties we have examined, so kinship is not necessary for the Deaf-World or any other group to qualify as an ethnic group (Barth, 1969; Petersen, 1980; Schneider, 1972; Sollors, 2001). Others say kinship should be taken in its social meaning as “those to whom we owe primary solidarity” (Schneider, 1969). “Ethnicity embody the sense of being a large unique family; the members feel knit to one another and so committed to the cultural heritage, which is the family’s inheritance” (A. D. Smith, 1986, p. 49). What is involved is a sense of tribal belonging, not necessarily genetic and blood ties. Certainly, there is a strong sense of solidarity in the Deaf-World; the metaphor of family goes far in characterizing many Deaf-World norms and practices.

What kinship is really about, other scholars contend, is a link to the past; it is about “intergenerational continuity” (Fishman, 1989). The Deaf-World does pass its norms, knowledge, language, and values from one generation to the next: first through socialization of the child by Deaf adults (parent or other) and second through peer socialization. Here, however, there is a significant difference from other ethnic groups: For many Deaf children, socialization into Deaf culture

starts late, usually when the Deaf child meets other Deaf children in school (Johnson & Erting, 1989). Members of the Deaf-World have a great handicap and a great advantage when it comes to intergenerational continuity. The handicap is that their hearing parents usually have a different ethnocultural identity that, lacking a shared language, they cannot pass on to their children. Moreover, they commonly do not advocate in the schools, community, courts, and so on for their Deaf child's primary language. Minority languages without parental and community support are normally endangered. The great advantage of the Deaf-World lies in the fact that there will always be intergenerational continuity for sign language because there will always be visual people who take possession of that language in preference to any other and with it the wisdom and values of generations of Deaf people before them. (Although one can imagine an intervention in the future that would provide high-fidelity hearing to Deaf children and thus threaten intergenerational continuity, it seems likely that most countries will not be able to afford it, and that most Deaf parents will continue to refuse such interventions with their Deaf children.)

When we think of kinship, yet other scholars maintain, what is at stake is common ancestors, what Joshua Fishman (1977) termed paternity—real or putative biological connections across generations. Johnson and Erting (1989) suggested that what is primary in this biological criterion for kinship is not genealogy but biological resemblance across generations. In that case, members of the Deaf-World are kin because Deaf people resemble one another biologically in their reliance on vision for language and for much else (Johnson & Erting, 1989). To some extent, like the members of many other ethnic groups, Deaf people come by their biological resemblance through heredity more often than not. The estimate commonly cited is 50% of all people born deaf with little or no usable hearing are so for hereditary reasons (Reardon et al., 1992). However, another 20% are Deaf for reasons unknown; many of those may be hereditarily Deaf people not aware of the role of their ancestry (S. Smith, 1995).

To summarize in the words of social scientist Arthur Smith

**Table 2** Deaf-World—hearing world boundaries

Deaf-World	Overlap	Hearing world
Sign language	Interpreter services	Spoken language
Social activities	Religious services	Law enforcement
Sign language teaching	Consumer goods and services	Employment (not Deaf related)
Political activities	Deaf history	Military services
Athletics	Deaf education	Garbage collection
Arts and leisure	Deaf service agencies	Medical care
Finding employment		Banking
Publishing		Transportation

By involving a collective name, by the use of symbolic images of community, by the generation of stereotypes of the community and its foes, by the ritual performance and rehearsal of ceremonies, by the communal recitation of past deeds and ancient hero's exploits, men and women partake of a collectivity and its historic fate which transcend their individual existences. (A. D. Smith, 1986, p. 46)

Many scholars in the field of ethnicity believe that these "internal" properties of the ethnic group just reviewed must also be accompanied by an "external" property, a boundary separating the minority from other ethnicities, in particular, the majority ethnicity (Barth, 1969). Does the Deaf-World in the United States occupy its own ecological niche? Does it look to itself for the satisfaction of certain needs, while looking to the larger society for the satisfaction of other needs—and conversely?

### Ethnic Boundaries

Table 2 shows, at the left, activities that are primarily conducted by Deaf people for Deaf people in the Deaf-World in the United States; at the right, activities in the hearing world that impact Deaf people; and in the middle, areas of overlap. The more Deaf people celebrate their language and culture, the more they affirm their distinct identity, the more they reinforce the boundary delineating them from the hearing world. Language comes first for it always plays a powerful role in maintaining ethnic boundaries, but especially so in the case of Deaf people because hearing people are rarely fluent in visual language and members of the

Deaf-World are rarely fluent in spoken language. Next, Deaf-World social activities are organized and conducted by Deaf people with little or no hearing involvement. On the other hand, law enforcement is a hearing world activity. Religious services overlap the Deaf and hearing worlds; there are missions to the Deaf, Deaf pastors, and signed services, but the operation of the house of worship is generally in hearing hands. All in all, the Deaf-World keeps to itself for many of its activities; it collaborates in a few with the hearing world; and it leaves the really broad responsibilities such as law enforcement to the larger society; in this, it is like other ethnic groups, such as Hispanic Americans.

This brief survey is intended to show that the Deaf-World in the United States today meets the criteria put forth for ethnic groups (also see Erting, 1978, 1982; Johnson & Erting, 1979, 1982, 1984, 1989; Markowicz & Woodward, 1978; Padden & Markowicz, 1976). Classifying the Deaf-World as an *ethnic group* should encourage those who are concerned with Deaf people to do appropriate things: learn their language, defend their heritage against more powerful groups, study their ethnic history; and so on. In this light, the Deaf-World should enjoy the rights and protections accorded other ethnic groups under international law and treaties, such as the United Nations Declaration of the Rights of Persons Belonging to National or Ethnic, Religious and Linguistic Minorities (United Nations, 2003a).

### Reasons Advanced to View the Deaf-World as a Disability Group

Is it also appropriate to label the Deaf-World a disability group? We do not ask whether Deaf people in fact have a disability because it is not a matter of fact: Disability, like ethnicity, is a social construct, not a fact of life, although it is a property of such constructs that they appear misleadingly to be a fact of life. For example, the social problem of alcoholism evidently consists of this: Many Americans suffer from alcoholism; there are specially trained people to help them (alcoholism counselors, psychologists, psychiatrists, and others) and special facilities to care for them, such

as detox centers. However, this understanding of alcoholism dates from the latter half of the 20th century. In the first half, the temperance movement branded excessive drinking as voluntary, and the movement promoted not treatment but prohibition. With the shift in the construction of alcoholism from illegal (and immoral) behavior to illness, the need was for medical research and treatment, halfway houses, hospital wards, outpatient clinics, and specialized hospitals (Gusfield, 1982).

Homosexuality went from moral flaw, to crime, to treatable disability, to a minority group seeking civil rights (Conrad & Schneider, 1980). Shortness came to be seen as a disability of childhood, not a normal variation, when growth enzyme was discovered, not before (Downie et al., 1996; Werth, 1991). Mild mental retardation came to be seen as a disability, not merely normal human variation in intellect, with the arrival of the IQ test (Gelb, 1987). In societies in which sign language use is mostly restricted to Deaf people, hearing people commonly see being Deaf as a serious problem requiring professional intervention; but in societies in which sign language use is widespread because of a substantial Deaf population—on Martha's Vineyard and Bali, for example—being Deaf is simply seen as a trait, not a disability (Lane, Pillard, & French, 2000).

The case of the forest dwellers of Central Africa is instructive. Their short stature, some 4.5 feet on average, allows them modest caloric requirements, easy and rapid passage through dense jungle cover in search of game, and construction of small huts rapidly disassembled and reassembled for self-defense and hunting. The Bantu villagers, formerly herdsman, now farmers, have contempt for the pygmies because of their puny size, and they in turn have contempt for the villagers who are “clumsy as elephants” in the forest, much too tall to move swiftly and silently; they “do not know how to walk” (Turnbull, 1962, p. 79). Each group considers the other handicapped by their physical size. Each fails to appreciate how physical makeup, culture, and environment are intertwined.

Despite all this evidence that disability is constructed in a given society at a given time, many writers addressing ethics and Deaf people, apparently unaware of disability studies and medical anthropology, simply adopt the naïve materialist view when it comes to

disability: "Almost by definition deaf persons . . . have a disability" (Gonsoulin, 2001, p. 554). "I maintain that the inability to hear is a deficit, a disability, a lack of perfect health" (D. S. Davis, 1997, p. 254). And, their ethical conclusions turn on this postulate. We understand, however, that disability is a label that can be applied with more or with less aptness to a particular group. That application is not a matter of chance, even less is it foreordained; it is powerfully influenced by the "technologies of normalization" (Foucault, 1980, p. 21) that exist to mitigate what is seen as a disability for they have a great stake in retaining that conception of the group. In the next section, arguments that have been made for including members of the Deaf-World among disability groups are examined critically.

### Oppression From Deaf Bodies

Advocates of classifying Deaf people with disability groups claim that Deaf people have this in common with people who avowedly have disabilities: They are discriminated against because general social customs do not accommodate their bodies. Deaf people are indeed discriminated against in school, on the job, and in gaining access, but it is much more their language that is the target of discrimination than their bodies: "The major impact of deafness is on communication" (Baynton, 2000, p. 391). Thus, the Deaf are more like oppressed language minorities than oppressed disability groups. Like many Hispanic Americans, for example, many Deaf people have difficulty learning in school because the teacher cannot communicate with them fluently; they have difficulty getting a job when the job requires good English; they miss out on important information because it has not been provided in their language.

Still, say the Deaf-are-disabled advocates, why not acknowledge the many things that physically different people share by using a common label (Baynton, 2002). After all, some disability activists make a claim for disability culture, just as there is a Deaf culture; many oppose mainstreaming, as do many Deaf activists. Both groups pay the price of social stigma, and stigmatized groups—among them disabled people, blacks, women, gays, and the Deaf—are often claimed to be biologically inferior. Moreover, both the Deaf-World and disability

groups struggle with the troubled-persons industries for control of their destiny (Gusfield, 1984). Both endeavor to promote their construction of their identity in competition with the efforts of professionals to promote *their* constructions (Finkelstein, 1981). Finally, because there are great differences among disability groups, accommodating one more with its unique issues need not be a problem.

At one level, oppressed minorities do indeed share important traits and a common struggle for the defense and valuing of their diversity. At that level, disabled people, blacks, women, gays, the Deaf, and other language minorities can inform and reinforce one another's efforts. They can promote an understanding of the value of diversity, learn successful strategies from one another, and use their combined numbers to urge government in the right directions. At another level, however, many practical truths apply only to individual minorities, with their own makeup, demographics, histories, and cultures. To minimize that diversity with the same global representation would undermine the most cherished goal of each group: to be respected and valued for its difference. After all, beyond being stigmatized because of their physical difference, what, practically speaking, do the Deaf have in common with gays, women, blacks, Little People, and people with mobility impairment, for example? Deaf people have been subject to the globalizing disability label, and it has widely led to the wrong questions and the wrong answers, which are considered later in this article under reasons to reject it. This is the pragmatic answer to disability scholar Lennard Davis's proposal that Deaf people abandon the category of ethnicity in favor of a coalition with gays, hearing children with Deaf parents, and people with disabilities (L. Davis, 2002): Their agendas are utterly different.

### The Shared Struggle for Rights

Another argument advanced for Deaf people to embrace the disability label is that it might assist them in gaining more of their rights (Baynton, 2002). For example, interpreters are not normally provided in the classroom for members of ethnic groups; Deaf people have them in many places under a disability umbrella. However, much that is important to Deaf people has

come through an understanding of the Deaf-World as an ethnic group. Let us cite the burgeoning of ASL in high schools and colleges in the United States and the increasing acceptance of ASL classes in fulfillment of the foreign language and culture requirement; the mushrooming of scholarship in the last 40 years concerning Deaf ethnicity—history, arts, social structure, culture, and language; the flourishing of the interpreting profession; the development of the discipline of Deaf studies; bilingual bicultural Deaf education; the growing community of nations that formally recognize their national sign language. All these gains reflect an understanding of the Deaf as an ethnic group.

Although the disability label seems inappropriate for the Deaf-World, its members have not aggressively promoted governmental understanding of its ethnicity and of the poor fit of the disability label. As a result, the majority's accommodation of the Deaf has come under a disability label, and Deaf people must in effect subscribe to that label to gain their rights in access to information, in education, and in other areas. This is the Deaf dilemma: retain some important rights as members of their society at the expense of being mischaracterized by that society and government or surrender some of those rights in the hope of gradually undermining that misconception. This dilemma is reminiscent of similarly oppressive choices offered to other minority groups: for gays to embrace the disability label and be spared classification as a criminal and entry into the army; for women to conform to the masculine idea of the feminine ideal and gain men's support and approval.

In principle, it should be possible for members of the Deaf-World in the United States to base their demand for language access on existing legislation and court rulings protecting language minorities. For example, in the field of education, the U.S. Congress has passed two types of statutes to remedy the disadvantage experienced by language-minority students who cannot communicate freely in the classroom by using their primary language: the Bilingual Education Act (P.L. 89-10, Title VII, 1965), which provides funding for a variety of programs promoting the use of minority languages in the schools, and civil rights statutes (P.L. 88-352, Title VI, 1964; P.L. 93-380,

1974), which impose an affirmative duty on the schools to give children who speak a minority language an equal educational opportunity by lowering the English language barriers. The provision of language rights in Deaf education should bring with it appropriate school curricula and materials, teachers who are ethnic models, interpreters, real television access through sign language, and video-telephone communication. But, in practice that would require that the public come to understand the Deaf-World as the Deaf-World understands itself. Until this happens, the Deaf-World can expect scant support from other ethnic groups.

Among the obstacles to a change from the disability to the ethnic construction of Deaf people are the numerous professional organizations predicated on the disability construction and who wish to own the problem of Deaf children. "To 'own' a social problem is to possess the authority to name that social condition a problem and to suggest what might be done about it" (Gusfield, 1989, p. 433). Consider just two of the many organizations that have Deaf children as clients. The American Academy of Otolaryngology, with over 10,000 members, has registered two paid lobbyists in Washington; the American Speech-Language-Hearing Association, with 115,925 members, has three (<http://sopr.senate.gov>). Members of these organizations collaborate with government officials in approving treatments, in drawing up legislation, and in evaluating proposed research and training activities. The Deaf-World has none of these advantages in seeking to promote an ethnic understanding of being Deaf.

#### Four Reasons to Reject the Disability Label

##### It "Doesn't Compute"

The overwhelming reason to reject the view of culturally Deaf people as members of a disability group concerns how Deaf people see themselves. People who have grown up Deaf and have become integrated into Deaf culture are naturally aware of their biological difference, but they do not, as a rule, see in that difference a reason to consider them members of a disability group. This is a very strong argument for rejecting the disability label because there is no higher authority on how a group should be regarded than the

members of the group themselves. Some writers, convinced that the Deaf have a disability and baffled by their refusal to acknowledge it, conclude that Deaf people are simply denying the truth of their disability to avoid stigma (Baynton, 2002; Finkelstein, 1991; Gonsoulin, 2001). But, many people have, like the Deaf, physical differences that are not accommodated (Zola, 1993)—relatively short and tall people, for example—and they also deny they have a disability. Surely, in doing so they are not simply trying to avoid stigma. The gender preferences of gay men and women were at one time viewed as an expression of mental illness. In rejecting that disability categorization, the gay rights movement was not simply trying to avoid a stigma; it was trying instead to promote a new representation of gay men and women that would be better for them, their families, and the wider society (Conrad & Schneider, 1980).

When Gallaudet University's president, I. King Jordan, was asked on the television program *Sixty Minutes* if he would like to be hearing, he replied: "That's almost like asking a black person if he would rather be white . . . I don't think of myself as missing something or as incomplete. . . . It's a common fallacy if you don't know Deaf people or Deaf issues. You think it's a limitation" (Fine & Fine, 1990). Deaf scholars like I. King Jordan, Tom Humphries, and MJ Bienvenu in the United States and Paddy Ladd in England are not rejecting the disability label because they want to avoid stigma associated with disability (Ladd, 2003). That would be to give them little credit. Rather, they are rejecting it because, as Tom Humphries has said so well, "It doesn't compute" (1993, pp. 6, 14). In ASL, the sign with a semantic field that most overlaps that of the English "disability" can be glossed in English LIMP-BLIND-ETC. I have asked numerous Deaf informants to give me examples from that category: They have responded by citing people in wheelchairs, blind people, mentally retarded people, and people with cerebral palsy, among others, but no informant has ever listed Deaf, and all reject it as an example of a disability group when asked.

Further examples of how the disability label does not compute come from Deaf preferences in marriage and childbearing. Like the members of many ethnic groups, culturally Deaf people prefer to socialize with

and to marry other members of their cultural group; as noted, the Deaf have one of the highest endogamous marriage rates of any ethnic group (Schein, 1989). When it comes to Deaf preferences in childbearing, there are no hard statistics, but in interviews with the press and with me, Deaf parents have expressed a wish for children like themselves—much as all parents do who do not see themselves as disabled. "I want my daughter to be like me, to be Deaf," one expectant Deaf mother declared in an interview with the *Boston Globe*. She explained that she came from a large Deaf family, all of whom had hoped that her baby would be born Deaf (Saltus, 1989; also see Mills, 2002). Other expectant Deaf parents reportedly say it will be fine either way, Deaf or hearing. These views contrast sharply with the tendency of disability groups. A study of blind people, for example, reported that they tend to shun the company of other blind people, associate with each other only when there are specific reasons for doing so, seek sighted mates, and do not wish to transmit their blindness to their children (Deshen, 1992). Leaders of the disability rights movement call for ambivalence: They want their physical difference valued, as a part of who they are; at the same time, they do not wish to see more children and adults with disabilities in the world (Abberley, 1987; Lane, 1995).

We should not be surprised that Deaf people want Deaf spouses, welcome Deaf children, and prefer to be together with other culturally Deaf people—in clubs, in school, at work if possible, in leisure activities, in political action, in sports, and so on—in short, they see being Deaf as an inherent good. Do not ethnic groups characteristically value their physical difference, from the pygmies of the Iturbi forest in Central Africa to the tall pale inhabitants of, say, Finland? Of course they do, so it is perfectly expected that culturally Deaf people positively value the Deaf difference and that hearing folks find in their own cultures a preference for hearing bodies, despite their poorer performance on some visual processing tasks compared to the Deaf (Lane, 2004a).

Thus, embracing the disability label in hopes it might assist Deaf people in gaining more of their rights is fundamentally flawed because Deaf people do not believe it. For Deaf people to surrender anyway to how others define them is to misrepresent themselves, and that is the first reason to reject the disability label.



## Greater Risk for the Deaf Child

There are many penalties for misrepresenting, for allowing the disability label. An important penalty concerns the risk to the Deaf child. It appears that children are at greater medical and surgical risk when their bodies differ from their parents in important ways that age alone does not explain. Parents want children like themselves, and if they are significantly unlike, they will listen to the doctors who say they can reduce or eliminate the difference, sometimes harming the child in the process. It is very tempting to locate the source of the social stigma with the child rather than the society; after all, the child is right there and much more manageable than an entire society. Moreover, the technologies of normalization are knocking at the door. However, the medicalization of difference deflects us from the real issue, which is the stigmatizing of difference in our society. When children who have undergone surgical normalizing become adults, many decry what was done to them as children.

For example, it has been the practice in the United States to operate on children with ambiguous genitalia, most often carving a vagina in male children because the surgical methods are not available to create a suitable penis. Once grown to adulthood, these and other intersexuals have been campaigning to dissuade urologists from continuing to perform this maiming surgery on children (Dreger, 1998). Little People, when their parents are not dwarfs, are frequently subjected as children to bone-breaking surgery for limb lengthening. It is painful, it is risky, and it is incapacitating. At best, it places the child in a no-man's land, neither short as a dwarf nor average size, and most adult dwarfs are utterly opposed to the surgery (Kennedy, 2003). There are many more victims of the medical-surgical imperative. One thinks of the horrors visited on the mentally ill, like frontal lobotomy (Valenstein, 1986), and those visited on homosexuals, such as deconditioning (Conrad & Schneider, 1980). Not all medical intervention in social issues is bad, of course; sometimes, it serves us well, and it derives great prestige from doing so. That is just why it overreaches at times and why we have to be wary of its abuse.

*Cochlear Implant Surgery.* Now to label the Deaf child as having a disability places that child at risk for

interventions like cochlear implant surgery. Cochlear implant surgery lasts about 3.5 hours under general anesthesia and requires hospitalization from 2 to 4 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 18 mm long is pushed through the opening. The wire seeks its own path as it moves around and up the coiled inner ear. The microstructure of the inner ear is destroyed; if there was any residual hearing in the ear, it is likely destroyed as well. 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.

*Clear Risks.* The surgery and general anesthesia entail medical and surgical risks. The incidence of bacterial meningitis in implanted children is 30 times higher than in age-matched unimplanted children (Daneshi et al., 2000; Reefhuis et al., 2003). Other risks include anesthesia risk (Svirsky, Teoh, & Neuburger, 2004); loss of vestibular function (Huygen et al., 1995); cerebrospinal fluid leak (Reefhuis et al., 2003); facial nerve stimulation and injury (Kelsall et al., 1997); and damage to the carotid artery (Gastman et al., 2002). The surgery can have fatal consequences (Jalbert, 2003). Nine of ten candidates for pediatric implant surgery, those with no or little usable hearing, were born Deaf (Allen, Rawlings & Remington, 1994; Center for Assessment, 1992). Such children rarely receive the main benefit sought: fluency in a spoken language (Lane & Bahan, 1998). Compounding the harm, special educators who work with the surgical team commonly urge oral educational programs on the parents and discourage sign language use (Tye-Murray, 1992). If implanted children are unable to learn spoken English and are prevented from mastering ASL, they will remain languageless for many years. Developmental milestones for signed languages are similar to those

for spoken languages, and the later the acquisition of ASL, the poorer its mastery on the average (Mayberry & Eichen, 1991; Newport, 1990; Petitto, 1993). It is inexcusable to leave a child without fluent language for years on end. Medicine is coming to realize that it is the overall quality of life of the person and not just the concerned organ that must be considered (Reisenberg & Glass, 1989).

*Dubious Benefits.* Advocates for childhood implantation acknowledge that “implants do not restore normal hearing,” and that, after the operation, “long-term habilitation continues to be essential” (Balkany et al., 2002, p. 356). According to a recent report, 59% of implanted children are judged by their parents to be behind their hearing peers in reading, and 37% are behind in math (Christiansen & Leigh, 2004). It seems unlikely these children will be full-fledged members of the hearing world (Lane, 1999; Lane & Bahan, 1998).

We know that early acquisition of ASL facilitates later mastery of English (Padden & Ramsey, 2000; Strong & Prinz, 1997). This linguistic intervention might deliver greater English mastery than implant surgery; the comparison study has not been done. On the contrary, every study that has compared the performance of children with cochlear implants to an unimplanted control group employed controls that apparently had not mastered any language (see, for example, the literature review in Geers, Nicholas, & Sedey, 2003).

*Ethics of Childhood Implant Surgery.* Thus, the surgery remains innovative despite more than a decade of use because research on language benefit and its parameters is very much a work in progress (see, for example, Svirsky, Teoh, & Neuburger, 2004). Also, there is no body of knowledge on the effects of the implant on educational achievement, social identity, or psychological adjustment. Optional innovative surgery on children is ethically problematic (Lane & Grodin, 1997).

It is hard to see how the pediatric implant surgeon can obtain informed consent from the parent, acting as moral agent for their child. Among the requirements for informed consent are a description of risks, but the physician cannot explain the risks of disturbed psychological,

social, and linguistic development because these have not been assessed by scientific research. Further, the surgeon must describe the benefits reasonably to be expected from pediatric cochlear implant surgery, but the variability of outcomes is so great that it is difficult to say what benefit any individual child will obtain. Of course, if the risks of cochlear implant surgery and its associated speech therapy and oral education outweigh the benefits, it should not be performed.

True informed consent would require the surgeon to disclose alternative procedures that might be advantageous for the subject, such as early association with Deaf peers and adults to ensure timely language acquisition, but otologists and audiologists are often uninformed about the Deaf-World and its language and disinclined to see that as an alternative.

There are also obstacles to informed consent on the parents' side. To recognize this is not to challenge the parents' legal and moral right to make decisions for their children, as some writers have disingenuously claimed (Balkany, Hodges, & Goodman, 1999; Eisenman, 1999; Hyde, 1994.) For surgeons, parental choice is a touchstone because they share with most parents a medical model of the Deaf child's status; thus, parental choice is surgeon's choice. Would the surgeons be as eager to extol parental choice if most parents declined the surgery?

The ethical basis for the parent acting as surrogate for the child is predicated on the assumption that the surrogate knows the child or is close to his or her cultural or ethical values. The surrogate's choices should approximate what the patient would have wanted were he or she able to express a choice (Ramsey, 1970). Unfortunately, hearing parents often do not know the patient because they have lacked a common language with their Deaf child. In fact, most Deaf children would likely refuse that consent to surgery if they were old enough to decide. We infer that because Deaf adults who were once Deaf children but are now old enough to make a considered decision are overwhelmingly opposed to pediatric implant surgery. Numerous Deaf organizations worldwide and the World Federation of the Deaf have formally protested childhood implant surgery (Lane, 1994). The National Association of the Deaf in the United States takes the position that Deaf children are healthy

babies; of course, surgery should not be performed on a healthy child. Their statement says in part:

Many within the medical profession continue to view deafness essentially as a disability and an abnormality and believe that deaf and hard of hearing individuals need to be 'fixed' by cochlear implants. This pathological view must be challenged and corrected by greater exposure to and interaction with well-adjusted and successful deaf and hard of hearing individuals. (National Association of the Deaf, 2000)

If medical and surgical procedures used with children who are Deaf, or intersexuals, or dwarfs required informed consent from adults *like* the child, they would almost never take place. And, when the parents are like the child, in fact they rarely take place.

Hearing parents of a Deaf child confront a challenge that is in some ways not unlike that faced by parents who adopt transracially. Both sets of parents have physical attributes markedly different from their children; in both cases, the children would normally become members of ethnic groups different from that of their parents. Are white foster parents of a black child, then, obliged to consider, or well-advised to consider, the views and interests of the black community? Many social workers believe so (Chimezie, 1975).

Likewise, hearing parents of a Deaf child would have much to gain from consulting Deaf adults. Deaf parents commonly raise Deaf and hearing children perfectly well without any surgery or other intervention by professionals. In fact, there is abundant research evidence that they do a better job on the average than hearing parents of Deaf children do, and hearing parents often have professional intervention (Lane, 1999; Lane et al., 1996). So, it is clear that it would be a needless error to place Deaf children at risk of the medical-surgical imperative by labeling the Deaf as a disability group. (Granted, there are disability groups that protest excessive surgical and medical intervention, but that is not a reasonable basis for considering Deaf children disabled.)

Why would such heroic medicine be practiced on young Deaf children who, moreover, cannot give their consent? For this to have happened, the plight of Deaf

children must be seen as truly desperate. In hearing society, deafness is indeed stigmatized. Sociologist Erving Goffman has distinguished three kinds of stigma: physical, characterological, and tribal. "There is only one complete, unblushing male in America," he explained. "[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" (Goffman, 1963, p. 128). Any deviation is likely to entail a stigma, and society tends to impute many when it finds a single one.

The layperson is misled not only by the common stigma associated with Deaf people in hearing society, but also, as countless parents of Deaf children have been misled, by some practitioners in fields such as otology, audiology and special education, and rehabilitation—the technologies of normalization—who paint the consequences of being Deaf in the most negative terms possible, thereby reaffirming the need for their services. Witness this outlandish claim by a pediatric implant team: "Deafness is the most disabling of disabilities" (Balkany, Hodges, & Goodman, 1996, p. 751). Cochlear implants are relatively new, but they are the latest stage in a long history in which the technologies of normalization have undertaken to make Deaf people more like hearing people. Each Deaf child in America is the scion of Deaf people across the ages; he or she receives a Deaf heritage and passes it on. Each Deaf child, then, experiences twice over the attempts by hearing people to change Deaf people, first as a theme of Deaf history and second as a theme of personal history, for rare is the Deaf child today in America who has not been subjected to such normalizing attempts—through surgery, through medicine, through therapy, through sacrificing education for sham speech. All these efforts nearly always are a failure for the 9 out of 10 Deaf children born Deaf.

When the first school for the Deaf in the Western world was established in Paris during the Enlightenment, painful surgical experiments on its pupils helped its resident doctor gain the title of founder of otology. His successor captured the view of Deaf children held by many surgeons then as now; he wrote: "The Deaf believe that they are our equals in all respects. We should be generous and not destroy that illusion. But whatever they believe, deafness is an infirmity and we

should repair it whether the person who has it is disturbed by it or not" (Menière, 1853). Like the members of other ethnic minorities, Deaf people are generally not disturbed by their identity, despite the need to struggle for their rights. Culturally Deaf people have always thought and think today that being Deaf is a perfectly good way to be, as good as hearing, perhaps better.

### Survival Risk for the Deaf-World

A third argument against the disability label for the Deaf-World concerns the risk to the Deaf-World as a whole if that representation prevails. A majority of people in the Deaf-World have inherited their ethnicity. Deaf inheritance and a failure to understand the ethnic status of culturally Deaf people have historically and at present placed the Deaf-World in jeopardy of ethnocide and even genocide. Despite surgical and medical experiments on large numbers of Deaf children in the 19th century, medicine made no inroads against the Deaf-World as a whole. However, developments in biology in the late 19th century gave rise to the eugenics movement, which sought to improve the race and eliminate the Deaf-World, among other groups considered undesirable, by selective breeding. From the point of view of the variety of humankind favored by selective breeding, the practice is eugenic; from the point of view of the varieties disfavored, it is genocidal.

The most famous advocate of regulating Deaf marriage to reduce Deaf childbirth was one of the founders of oral education in America, Alexander Graham Bell, who devoted his great wealth and prestige to these eugenic measures (Lane, 1984). When the American Breeders Association created a section on eugenics "to emphasize the value of superior blood and the menace to society of inferior blood," Bell agreed to serve. He engaged the issue of eugenics and the Deaf population beginning in the 1880s. Sign language and residential schools were creating a Deaf community, he warned, in which Deaf people intermarried and reproduced, a situation fraught with danger to the rest of society. He sounded the alarm in his *Memoir Upon the Formation of a Deaf Variety of the Human Race*, presented to the National Academy of Sciences in 1883. Because there are familial patterns of deafness,

Bell wrote, "It is to be feared that the intermarriage of such persons would be attended by calamitous results to their off-spring" (Bell, 1883, p. 11).

Bell argued, with breathtaking hubris, that to avoid this calamity, we must "commence our efforts on behalf of the deaf-mute by changing his social environment" (1883, p. 46). Residential schools, where most Deaf children acquired language, identity, and a life partner, should be closed and Deaf people educated in small day schools. Sign language should be banished; Deaf teachers fired. Bell's *Memoir* received wide newspaper coverage. Bell's actions led many to believe that there would be, or already were, laws prohibiting Deaf marriage. There was much consternation among Deaf people contemplating marriage. Some hearing parents of Deaf children chose to have their children sterilized (Mitchell, 1971).

A 1912 report from Bell's eugenics section of the Breeders' Association cites his census of blind and Deaf persons and lists "socially unfit" classes to "be eliminated from the human stock" (American Genetic Association, 1912, p. 3). The model eugenic law called for the sterilization of feeble-minded, insane, criminalistic ("including the delinquent and the wayward"), epileptic, inebriate, diseased, blind, Deaf, deformed, and dependent people ("including orphans, ne'er-dowells, the homeless, tramps, and paupers"). By the time of World War I, 16 states in the United States had sterilization laws in force. By 1940, 30 states had such laws (Haller, 1963). Physicians were actively involved in this eugenics movement (May & Hughes, 1987).

The eugenics movement as it concerned Deaf people worldwide has only recently been receiving the study it deserves (Biesold, 1999; Schuchman & Ryan, 2002). When National Socialism came to power in Germany, teachers of Deaf students advocated adherence to the hereditary purity laws, including the sterilization of congenitally Deaf people. Deaf schoolchildren were required to prepare family trees, and the school reported those children who were congenitally Deaf or who had a Deaf relative to the department of health for possible sterilization (Muhs, 1996).

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” (Peter, 1934, p. 187). The 1933 census showed 45,000 “deaf and dumb” persons in a total population of over 66 million. An estimated 17,000 of these Deaf Germans, a third of them minors, were sterilized. In 9% of the cases, sterilization was accompanied by forced abortion. An additional 1600 Deaf people were exterminated in concentration camps in the 1940s; they were considered “useless eaters,” with lives unworthy of being lived (Biesold, 1999; Higgins, 1993). As in the United States, the medical profession was the certifying authority for forced sterilization.

### Deaf Eugenics Today

Audiometric testing, labeling, special needs schooling, genetic research and counseling, surgery, and reproductive control all are means of currently or potentially exercising power over the Deaf body. In 1992, researchers at Boston University announced that they had identified the so-called 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” (“BU Team,” 1992, p. 6; “Deafness gene,” 1992, p. 141). The goal of such efforts as gene transfer therapy is, of course, to reduce Deaf births, ultimately altogether. Thus, a new form of medical eugenics applied to Deaf people is envisioned, in this case by an agency of the U.S. government. The primary characteristics of Deaf people with this particular genetic background to be eliminated are numerous Deaf relatives, sign language fluency, facial features such as widely spaced eyebrows, and coloring features such as white forelock and freckling (Fraser, 1976).

Imagine the uproar if medical scientists trumpeted a similar breakthrough for any other ethnic minority, promising a reduction in that ethnic group’s children—promising fewer Navajos, fewer Jews, whatever the ethnic group. The Australian government indeed undertook a decades-long eugenic program to eliminate its aboriginal peoples by placing their children in

white boarding houses in the city, where it was hoped they would marry white and have white children. In 1997, a government commission of inquiry classified these and other measures as genocide (National Inquiry, 1997). Under international law, an activity that has the foreseeable effect of diminishing or eradicating a minority group, even if it is undertaken for other reasons and is not highly effective, is guilty of genocide (National Inquiry, 1997; United Nations, 2003b). Why do governments fail to apply this moral principle and law to the Deaf? Americans fail to see the danger of pursuing a genocidal program in this instance because most Americans see Deaf people as having a disability arising from an impairment. And, the goal of eradicating a disability, although it may be in some circumstances unwise and unethical, is not seen as genocide.

If culturally Deaf people were understood to be an ethnic group, they would have the protections offered to such groups. It is widely held as an ethical principle that the preservation of minority cultures is a good. The variety of humankind and cultures enriches all cultures and contributes to the biological, social, and psychological well-being of humankind. Laws and covenants, such as the United Nations Declaration of the Rights of Persons Belonging to National or Ethnic, Religious and Linguistic Minorities (United Nations, 2003a), are founded on a belief in the value of protecting minority cultures. The declaration calls on states to foster their linguistic minorities and ensure that children and adults have adequate opportunities to learn the minority language. It further affirms the right of such minorities to enjoy their culture and language and participate in decisions on the national level that affect them. Programs that substantially diminish minority cultures are engaged in ethnocide and may constitute crimes against humanity.

Among the biological means sought for regulating and, ultimately, eliminating Deaf culture, language, and people, cochlear implants have historical antecedents, then, in medical experimentation on Deaf children and reproductive regulation of Deaf adults. There is now abundant scientific evidence that the Deaf-World has the properties of an ethnic group. Many Americans, perhaps most, would agree that society should not seek the scientific tools or use them, if available, to change

a child biologically so he or she will belong to the majority rather than the minority, even if society believes that this biological engineering might reduce the burdens the child will bear as a member of a minority. Even if children destined to be members of the African American, Hispanic American, Native American, or Deaf American cultures could be converted with biopower into white, Caucasian, hearing males—even if society could accomplish this, it should not. Here lies the answer to bioethicist Dena Davis, who has argued that it would be wrong to withhold a perfect implant from a Deaf child, for the Deaf-World is a limiting one and withholding the implant would be to reduce the child's possibilities in life; it would violate the child's right to an "open future" (D. S. Davis, 1997, p. 256). It is true that minority members frequently have a less-open future than majority members; yet, we all would agree that surgery sought to help a child "pass" as a member of the majority, or simply to facilitate learning the majority language, is unethical. Why does Davis endorse such surgery on the Deaf child but not on the black one? Because she continues to see the Deaf child as disabled.

Surgeons have made the claim that a Deaf child is not yet a member of the Deaf-World, and thus a program of implanting Deaf children should not be viewed as undermining that ethnic minority (Cohen, 1994). In fact, Deaf people should mind their own business, they imply, because young Deaf children of hearing parents are not culturally Deaf. Because much turns on this point, it is worth considering the logic of how we make cultural assignments. There seem to be three possible premises: the infant belongs to no culture at all until a certain age or stage of development; the infant has the culture of his or her parents from birth; or the infant has the cultural affiliation he or she will normally acquire. Now, it is a fact that the child is launched at the moment of birth onto a trajectory that, depending on the child's makeup and environment, will normally lead him or her to master a particular language and culture natively. It is this potentiality in the newborn Native American child, for example, that leads us to say that child *is* Native American (not *will be*) although the child has not yet acquired the language and culture that go with that cultural attribution. In making this attribution, we would not ask first about

the parents' culture. Their physical makeup and culture (their ethnicity), although usually consonant with their child's, does not itself decide the child's cultural assignment; it is the makeup of the child that does. With adoptive parents or even a surrogate mother, the child with Native American constitution would be called Native American. Thus, a program of adopting such infants into Caucasian homes would be guilty of undermining Native American culture, and its proponents could not deny it on the grounds that the children had not yet learned that culture and its language.

Ethicist Dena Davis, responding to my article with Michael Grodin on "Ethical Issues in Cochlear Implant Surgery," disputed these claims: "I reject the notion that physical characteristics . . . constitute cultural membership" (D. S. Davis, 1997; Lane & Grodin, 1997). However, it is undeniable that culture and physical characteristics are at times obviously intertwined and mutually reliant. To return to the example of the forest dwellers, their culture is very much associated with their height in its coupling to their environment. Pygmies hunt in groups of six or seven families, each with its own hunting net; the women and children drive the animals into the long circle of nets joined end to end, and the take is shared. In view of net hunting, close reciprocal collaboration is needed in many facets of life. That may be the reason that pygmy families in a hunting group live together in a closed circle of small conical huts. The maintenance of law is also a cooperative affair, as is worship. All these pygmy cultural issues—cooperative hunting, living, justice, and worship—seem to have their roots in the pygmies' physical characteristics. To cite a more widespread example of physical characteristics associated with culture, gender has profound consequences for acculturation in most of the nations of the world, if not all. It is this association between physical characteristics and culture that no doubt leads to the principle of cultural attribution stated above: Infants have the culture their makeup would normally yield. An intervention like transracial adoption can override the expected outcome (Nunes, 2001). In that case, the black child, for example, might not have the opportunity to acquire the language and culture of his ethnic group, but he or she remains black nonetheless, according to our society's rules of cultural attribution. The same

phenomenon occurs with Deaf children; they commonly have delayed access to Deaf culture and language because their parents are unable or disinclined to give them that access. Only a minority of black children find themselves in this predicament; a majority of Deaf children do.

Hence, the newborn Deaf child *is* culturally Deaf (hence my use of capital-D Deaf) and a program of implanting Deaf children does indeed undermine that ethnic minority. To see the link more clearly, imagine that the program had perfect implants: If there were no Deaf children, there would be no Deaf-World. The Deaf infant may not yet have acquired the language and culture that are, given its makeup, its natural right and heritage, those it will prize as an adult (because most born-Deaf people do), but the child's life trajectory is surely headed there; it uses vision almost exclusively, it communicates visually not aurally. The child may have hearing biological parents, but this child is not a hearing person both in principle, as we have seen, and in practice. As a matter of practice, if the parents cannot communicate fluently with their child, they will be severely hampered in teaching the child their language and culture, and the child can never acquire them natively, without instruction, as a hearing child would. However adept hearing parents may be, they cannot model Deaf adulthood, only hearing adulthood, and a child who relies primarily on vision will never develop into a hearing person, not remotely. The parents, on the other hand, will never be culturally Deaf. Thus, uncommon as it may be among other cultures, Deaf children and their parents very often do not share the same cultural membership.

The U.S. Indian Child Welfare Act of 1978 was passed at a time when the survival of Native American cultures was considered threatened by very high rates of transracial adoption. The act was designed to prevent the undermining of Native American tribes, stating that "it is the policy of this nation to protect the best interests of Indian children and to promote the stability and security of Indian tribes" (Simon & Altstein, 1992, pp. 18–19). The social issues leading to the act were in many ways specific to that minority, but the dual principle the Congress recognized was general: protect the child *and* protect the ethnic group. The Supreme Court ruled that lower courts must

consider the best interests of the particular Indian tribe as well as the best interests of the child (Simon & Altstein, 1992). Do the ethical principles applied here not apply equally well to other ethnic groups, including the Deaf?

As members of a stigmatized minority, Deaf children's lives will be full of challenge, but, by the same token, they have a special contribution to make to their own community and the larger society. The more children born Deaf are viewed not as members of a minority culture but as disabled, the more society is prepared to conduct surgery of unproven benefit and unassessed risk, ignoring the harm that is done to the child's ethnic group. The representation of Deaf people determines the outcome of society's ethical judgment.

### Wrong Solutions

Because they are an ethnic group whose language and mores were long disparaged, Deaf people commonly feel solidarity with other oppressed groups, the more so as the Deaf-World includes such groups as people with disabilities, seniors, women, blacks, and so on. Deaf people have special reasons for solidarity with hard-of-hearing and late-deafened people; their combined numbers have created services, commissions, and laws that the Deaf-World alone probably could not have achieved. Solidarity, yes, but when culturally Deaf people allow their ethnic identity to be subsumed under the construct of disability, they set themselves up for wrong solutions and bitter disappointments. After all, members of the Deaf-World differ from disabled people in their language and cultural experience, in their body of knowledge, in their system of rules and values, and in their models for selfhood.

If the Deaf-World were to embrace a disability identity, it would urge on Americans an understanding from which grow solutions that Deaf people oppose. Priorities of the disabilities rights movement include better medical care, rehabilitation services, and personal assistance services (Shapiro, 1993). Deaf people do not attach particular importance to any of these services and instead campaign for acceptance of their language and better and more interpreters. Whereas the disability rights movement seeks

independence for people with disabilities, Deaf people cherish interdependence with other Deaf people. These differences in values and priorities far outweigh the areas, such as fighting job discrimination, in which Deaf goals are potentially advanced by joining ranks with disability groups.

Disability advocates think of Deaf children as disabled, and thus those advocates have endeavored to close the special schools, where Deaf children gained language and a proud identity, and to absurdly plunge Deaf children into hearing classrooms and a thoroughly exclusionary environment called *inclusion* (Lane, 2004b). It is because government is allowed to proceed with a disability construction of Deaf ethnicity that the U.S. Office of Bilingual Education and Minority Language Affairs does not provide special resources for schools with large numbers of ASL-using children, although the law requires it to do so for schools with large numbers of students whose best language is not English.

As explained, there were landmark court rulings in the United States under the Civil Rights Act and the Equal Educational Opportunities Act that require schools with children who have “limited English proficiency” to provide instruction initially using the children’s native language. The Code of Federal Regulations quite sensibly defines *native language* as the language normally used by the individual (500.4; 34 CFR Ch. V 7-1-87 edition). Deaf children’s native language is sign language (provided, of course, that they are given an opportunity to acquire it). Deaf children have a particularly strong claim on bilingual education because, like many members of other ethnic groups but more so, they will never make a transition to full use of English and will always require an important part of their instruction in their best language. It is because of the disability construction of Deaf people that those laws have not been applied to ASL-using children. It is because of the disability construction that the teachers most able to communicate with America’s Deaf children are excluded from the profession on the grounds that they have a disqualifying disability. It is because lawmakers see Deaf people as disabled that, following the Deaf revolution at Gallaudet University, the Congress passed a law, not recognizing ASL or the Deaf-World as an ethnic

minority, but establishing another institute of *health*, the National Institute on Deafness and Other Communication Disorders, operated by the Deafness troubled-persons industry, and sponsoring research to reduce the numbers of Deaf people.

This article has presented a case that the sign language-using minority in the United States, the Deaf-World, is best viewed as an ethnic group, and it has cited reasons why it is inappropriate to view the Deaf-World as a disability group: Deaf people themselves do not believe they have a disability; the disability construction brings with it needless medical and surgical risks for the Deaf child; it also endangers the future of the Deaf-World. Finally, the disability construction brings bad solutions to real problems because it is predicated on a misunderstanding.

All of these objections to the disability construction of culturally Deaf people apply to the proposal that Deaf people be understood as both an ethnic group and a disability group at the same time. Taking up such a position would weaken the Deaf-World claim on ethnicity (is there any other ethnic group that is a disability group?) while inviting the risks and wrong solutions described here. The ethically troubling practices in which surgeons, scientists, and educators are engaged—operating on healthy Deaf children, seeking the means to diminish and ultimately eradicate the Deaf-World, opposing the Deaf child’s right to full and fluent language—exist because this ethnic group is misunderstood as a disability group. They will not be avoided by affirming, contrary to the group’s own judgment, that it is a disability group but also an ethnic group.

How we ultimately resolve these ethical issues goes well beyond Deaf people; it will say a great deal about what kind of society we are and the kind of society in which we wish to live. Difference and diversity not only have evolutionary significance but, I would argue, are a major part of what gives life its richness and meaning; ethnic diversity is a basic human good, and to choose to be with one’s own kind is a fundamental right. There is reason for hope: Society *can* adopt a different understanding of a people. Native Americans were once seen as savages; black Americans as property; women as utterly dependent. The case for



Deaf ethnicity built by the social sciences is powerful. Increasingly, linguists take account of ASL, sociologists of the social structure of the Deaf-World, historians of its history, educators of its culture, and so on. It remains to reform those other professions that have an outdated understanding or a representation that suits their agenda but not that of Deaf people. The challenge to the professions that seek to be of service to Deaf children and adults is to replace the normativeness of medicine with the curiosity of ethnography.

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