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## Construction of Deafness

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### Social Problems Are Constructed

It is obvious that our society is beset by numerous social problems. A brief historical perspective on four of them reveals something not so obvious: social problems are constructed in particular cultures, at particular times, in response to the efforts of interested parties.

The social problem of alcoholism evidently consists in this: there is a particular segment of the population that suffers from the use of alcohol; these sufferers need specially trained people to help them—for example alcoholism counselors, psychologists and psychiatrists; they need special facilities such as detoxification centers; and special organizations like AA. This understanding of alcoholism is less than fifty years old. Recall that the Temperance Movement of the last century viewed excessive drinking not as a disease but as an act of will; alcoholics victimized their families and imposed on the rest of society. The movement advocated not treatment but prohibition. Some groups favored prohibition and took the moral high ground; other groups felt justified in breaking the law. Special facilities existed then to house and treat many problem groups—mentally ill people, for example—but not people who drank too much. Only recently has a consensus developed that excessive drinking “is” a disease—a matter of individual suffering more than a political dispute. With this shift in the construction of alcoholism and alcoholics—from victimizers to victims—the evident need was for medical research to alleviate suffering; vast sums of money are now devoted to research on alcoholism, and there is now a large treatment establishment with halfway houses, hospital wards, outpatient clinics, and specialized hospitals (Gusfield, 1982).

The discovery of child abuse dates from the 1950s. Radiologists and pediatricians first decried the evidence they were seeing of parents beating their children. The Children’s Bureau and the media took up the cause (it is still very present in TV and the newspapers) and made the public aware of this social problem. In the decade that followed, the states passed laws requiring reports of child abuse and providing penalties. Of course, parents did not start beating their children only in the 1950s. Rather, a social consensus emerged in that decade that a problem existed requiring laws, special welfare workers, and special budgetary provisions. In the last century, the major problems associated with children concerned poverty and child labor—a rather different and much more political construction of the problem of improper treatment of children (Gusfield, 1989).

For a very long time, the dominant construction of homosexuality, like that of alcoholism, was a moral one: men and women were making sinful choices; the problem was “owned” by the church. Later psychiatry gave it a new construction: it “is” an illness they claimed that psychiatrists could treat (Conrad & Schneider, 1980). In the third phase, Gays and Lesbians were presented as a minority group; they ask for the same protection as all other groups that are discriminated against based on the circumstances of their birth, such as blacks and women.

Disability, too, has had moral, medical and now social constructions, as numerous articles in this journal have explicated. The Disability Rights Movement has shifted the construct of disability “off

the body and into the interface between people with impairments and socially disabling conditions” (Hevey, 1993, p. 426).

Alcoholism has changed from a moral failure to a disease; child abuse from an economic problem to a criminal one; homosexuality from disease to personal constitution to human rights; disability from tragic flaw to social barriers. Social problems, it seems, are partly what we make of them; they are not just out there “lying in the road to be discovered by passers-by” (Gusfield, 1984, p. 38). The particular way in which society understands alcoholism, disability and so forth determines exactly what these labels mean, how large groups of people are treated, and the problems that they face. Deafness, too, has had many constructions; they differ with time and place. Where there were many deaf people in small communities in the last century, on Martha’s Vineyard, for example, as in Henniker, New Hampshire, deafness was apparently not seen as a problem requiring special intervention. Most Americans had quite a different construction of deafness at that time, however: it was an individual affliction that befell family members and had to be accommodated within the family. The great challenge facing Thomas Gallaudet and Laurent Clerc in their efforts to create the first American school for the deaf was to persuade state legislatures and wealthy Americans of quite a different construction which they had learned in Europe: Deafness was not an individual but a social problem, deaf people had to be brought together for their instruction, special “asylums” were needed. Nowadays, two constructions of deafness in particular are dominant and compete for shaping deaf peoples’ destinies. The one construes deaf as a category of disability; the other construes deaf as designating a member of a linguistic minority. There is a growing practice of capitalizing Deaf when referring specifically to its second construction, which I will follow hereafter.

## Disability vs. Linguistic Minority

Numerous organizations are associated with each of the prominent constructions of deafness. In the U.S., National organizations primarily associated with deafness as disability include the A. G. Bell Association (4,500 members), the American Speech-Language-Hearing Association (40,000), the American Association of Late-Deafened Adults (1,300), Self-Help for the Hard of Hearing (13,000), the American Academy of Otolaryngology, Head and Neck Surgery (5,600), and the National Hearing Aid Society (4,000). National organizations associated primarily with the construction of Deaf as a linguistic minority include the National Association of the Deaf (20,000), the Registry of Interpreters for the Deaf (2,700), and the National Fraternal Society of the Deaf (13,000) (Van Cleve, 1987; Burek, 1993).

Each construction has a core client group. No one disputes the claim of the hearing adult become deaf from illness or aging that he or she has a disability and is not a member of Deaf culture. Nor, on the other hand, has any one yet criticized Deaf parents for insisting that their Deaf child has a distinct linguistic and cultural heritage. The struggle between some of the groups adhering to the two constructions persists across the centuries (Lane, 1984) in part because there is no simple criterion for identifying most childhood candidates as clients of the one position or the other. More generally, we can observe that late deafening and moderate hearing loss tend to be associated with the disability construction of deafness while early and profound deafness involve an entire organization of the person’s language, culture and thought around vision and tend to be associated with the linguistic minority construction.

In general, we identify children as members of a language minority when their native language is not the language of the majority. Ninety percent of Deaf children, however, have hearing parents who are unable to effectively model the spoken language for most of them. Advocates of the disability construction contend these are hearing-impaired children whose language and culture (though they may have acquired little of either) are in principle those of their parents; advocates of the linguistic

minority construction contend that the children's native language, in the sense of primary language, must be manual language and that their life trajectory will bring them fully into the circle of Deaf culture. Two archetypes for these two constructions, disability and linguistic minority, were recently placed side by side before our eyes on the U. S. television program, "Sixty Minutes." On the one hand, seven-year-old Caitlin Parton, representing the unreconstructed disability-as-impairment: presented as a victim of a personal tragedy, utterly disabled in communication by her loss of hearing but enabled by technology, and dedicated professional efforts (yes, we meet the surgeon), to approach normal, for which she yearns, as she herself explains. On the other hand, Roslyn Rosen, then president of the National Association of the Deaf, from a large Deaf family, native speaker of ASL, proud of her status as a member of a linguistic minority, insistent that she experiences life and the world fully and has no desire to be any different (*Sixty Minutes*, 1992).

### Professional Influence over Constructions

Organizations espousing each construction of deafness compete to "own" the children and define their needs. Their very economic survival depends on their success in that competition. Which construction of a social problem prevails is thus no mere academic matter. There is a body of knowledge associated with construction A and a quite different body with construction B; the theories and facts associated with construction A have been studied by the professional people who grapple with the social problem; they are the basis of their specialized training and professional credentials and therefore contribute to their self-esteem; they are used to maintain respect from clients, to obtain federal and state funding, to insure one's standing in a fraternity of like professionals; they legitimize the professional person's daily activities. Professionals examine students on this body of knowledge, give certificates, and insert themselves into the legal and social norms based on their competence in that body of knowledge. Whoever says A is a mistaken construction is of course not welcome. More than that, whoever says A is a construction is not welcome, for that implies that there could be or is another construction, B, say, which is better. What the parties to each construction want is that their construction not be seen as a construction at all; rather, they insist, they merely reflect the way things are in the world (cf. Gusfield, 1984).

These "troubled-persons industries," in the words of sociologist Joseph Gusfield, "bestow benevolence on people defined as in need" (Gusfield, 1989, p. 432). These industries have grown astronomically in recent decades (Albrecht, 1992). The professional services fueled by the disability construction of deafness are provided by some administrators of schools and training programs, experts in counseling and rehabilitation, teachers, interpreters, audiologists, speech therapists, otologists, psychologists, psychiatrists, librarians, researchers, social workers, and hearing aid specialists. All these people and the facilities they command, their clinics, operating rooms, laboratories, classrooms, offices and shops, owe their livelihood or existence to deafness problems. Gusfield cites the story about American missionaries who settled in Hawaii. They went to do good. They stayed and did well (Gusfield, 1989).

The troubled-person professions serve not only their clientele but also themselves, and are actively involved in perpetuating and expanding their activities. Teachers of the Deaf, for example, seek fewer students per teacher and earlier intervention (Johnson *et al.*, 1989). American audiologists have formally proposed testing of the hearing of all American newborns without exception. The self-aggrandizement of the troubled-persons professions when it comes to Deaf people is guided by a genuine belief in their exclusive construction of the social problem and their ability to alleviate it. Some of their promotional methods are readily seen; for example, they employ lobbyists to encourage legislation that requires and pays for their services. Other measures are more subtle; for example, the structural relation between the service provider and the client often has the effect of disempowering the client and maintaining dependency.

## Lessons from Services for Blind People

The history of services to blind people illustrates some of the pitfalls of the professionalization of a social problem. Workshops for blind people have large budgets, provide good income for sighted managers, and have a national organization to lobby for their interest. Blind people, however, commonly view sheltered workshops as a dead end that involves permanent dependency. The editor of the journal *Braille Monitor* says that “professional” is a swear word among blind people, “a bitter term of mockery and disillusionment” (Vaughan, 1991). A light-house for the blind was raked over the coals in that journal for having one pay scale for blind employees and a higher one for sighted employees performing the same work; moreover, the blind employees were paid below minimum wage (*Braille Monitor*, 1989). The National Accreditation Council for Agencies Serving the Blind and visually Handicapped (NAC) was disowned by organizations of blind people for its efforts to keep blind people in custodial care, its refusal to hear blind witnesses, and its token representation of blind people on the board; the Council rebutted that it had to consider the needs of agencies and professionals and not just blind people. For decades blind people picketed the NAC annual meetings (*Braille Monitor*, 1973; Jernigan, 1973; Vaughan, 1991).

A conference convened to define the new specialization of mobility trainer for the blind concluded that it required graduate study to learn this art and that “the teaching of mobility is a task for the sighted rather than a blind individual” (quoted in Vaughan, 1991, p. 209). This approach was naturally challenged by blind consumers. At first, the American Association of Workers with the Blind required normal vision for certification; then this was seen as discriminatory, in violation of section 504 of the Rehabilitation Act of 1973. So the criteria were changed. To enter the training program, the student must be able to assess the collision path of a blind person with obstacles nearly a block away. As it turns out, the functions claimed to be essential to mobility teaching just happen to require normal vision. Needless to say, blind people have been teaching blind people how to get about for centuries (Olson, 1981).

Workers with blind people view blindness as a devastating personal tragedy although blind people themselves commonly do not. Said the president of the National Association of the Blind “We do not regard our lives . . . as tragic or disastrous and no amount of professional jargon or trumped up theory can made us do so” (Jernigan quoted in Olson, 1977, p. 408). As sociologist R. A. Scott explains in his classic monograph, *The Making of Blind Men*, the sighted professionals believe that the blind man’s only hope for solving his problems is to submit to their long-term program of psychological services and training. To succeed, the blind man is told, he must change his beliefs about blindness, most of all, his belief that he is basically fine and only needs one or two services. The cooperative client is the one who welcomes all the services provided; the uncooperative client is the one who welcomes all the services provided; the uncooperative client is the one who fails to realize how many and great his needs are—who is in denial. The troubled-persons industries thus stand the normal relation between needs and services on its head: services do not evolve purely to meet needs; clients must recognize that they need the services provided by the professionals. Scott comments that it is easy to be deluded about the reality of these special needs. There are always a few blind clients who can be relied on to endorse these beliefs in the profound need for professional services. These blind individuals have been socialized, perhaps since childhood, to the professional construction of blindness. They confirm that blind people have the needs the agency says they have (Scott, 1981).

So it is with deafness. In much of the world, including the United States, deaf people are largely excluded from the ranks of professionals serving deaf children. In many communities it just happens that to be a teacher of deaf children you must first qualify as a teacher of hearing children, and deaf people are excluded as teachers of hearing children. In other communities, it just happens that to become a teacher of deaf children the candidate who is most capable of communicating with them is disbarred because he or she must pass an examination couched in high register English without an interpreter. And as with services for blind people, many of the professions associated with the disability

construction of deafness insist that the plight of the deaf child is truly desperate—so desperate, in fact, that some professionals propose implant surgery followed by rigorous and prolonged speech and hearing therapy. The successful use of a cochlear implant in everyday communication calls on a prior knowledge of spoken language (Staller *et al.*, 1991) that only one child candidate in ten possesses (Allen *et al.*, 1994); this has not, however, deterred professionals from recruiting among the other ninety percent; it is doubtful that the cochlear-implant industry would survive, certainly not flourish, if it sold its services and equipment only to the core clientele for the disability construction.

As with service providers for blind people, the troubled-persons industry associated with deafness seeks total conformity of the client to the underlying construction of deafness as disability. In the words of an audiology textbook: “One is not simply dealing with a handicapped child, one is dealing with a family with a handicap” (Tucker & Nolan, 1984 quoted in Gregory & Hartley, 1991, p. 87). The text goes on to state: “This concept of ‘total child’ being child plus hearing aids is one which parents may need time to come to terms with and fully accept.” The profession wants to intervene in that family’s life as early as possible and seeks to provide “a saturation service” (Tucker & Nolan, 1984 quoted in Gregory & Hartley, 1991, p. 97).

The criteria for disability, presented as objective, in fact conform to the interests of the profession (Oliver, 1990). Audiologic criteria decide which children will receive special education, so the audiologist must be consulted. In most countries of the world, audiology and special education are intimately related; the role of special education is to achieve as far as possible what audiology and otology could not do—minimize the child’s disability. Writes one audiologist: “Education cannot cure deafness; it can only alleviate its worst effects” (Lynas, 1986, quoted in Gregory & Hartley, 1991, p. 155). Parents generally have little say about the right educational placement for their child; neither are there any functional tests of what the child can understand in different kinds of classrooms. Instead, audiologic criteria prevail, even if they have little predictive value. For example, the academic achievement scores of children classified as severely hearing-impaired are scarcely different from those of children classified as profoundly hearing impaired (Allen, 1986). Research has shown that some children categorized as profoundly hearing impaired can understand words and sentences whereas others do not even detect sound (Osberger *et al.*, 1993). Likewise, Scott states that the official definition of blindness is “based upon a meaningless demarcation among those with severely impaired vision” (Scott, 1981, p. 42).

## The Making of Deaf Men

The family that has received “saturation services” from the deafness troubled-persons industry will participate in socializing the deaf child to adapt the child’s needs to those of the industry. A recent handbook for parents with implanted children states: “Parents should accept a primary role in helping their child adjust to the implant. They must assume responsibility for maintaining the implant device, for ensuring that the child is wearing it properly, and assuring that the auditory speech stimulation occurs in both the home and school” (Tye-Murray, 1992, p. xvi). “The child should wear the implant during all waking hours” (Tye-Murray, 1992, p. 18). Ultimately, the child should see the implant as part of himself, like his ears or hands. The handbook recounts enthusiastically how one implanted schoolchild, told to draw a self-portrait, included the speech processor and microphone/transmitter in great detail: “This self-portrait demonstrated the child’s positive image of himself and the acceptance of his cochlear implant” (Tye-Murray, 1992, p. 20).

The construction of the deaf child as disabled is legitimized early on by the medical profession and later by the special education and welfare bureaucracy. When the child is sent to a special educational program and obliged to wear cumbersome hearing aids, his or her socialization into the role of disabled person is promoted. In face-to-face encounters with therapists and teachers the child learns to cooperate in promoting a view of himself or herself as disabled. Teachers label large numbers of

these deaf children emotionally disturbed or learning disabled (Lane, 1992). Once labeled as “multiply handicapped” in this way, deaf children are treated differently—for example, placed in a less demanding academic program where they learn less, so the label is self-validating. In the end, the troubled-persons industry creates the disabled deaf person.

## Deaf as Linguistic Minority

From the vantage point of Deaf culture, deafness is not a disability (Jones & Pullen, 1989). British Deaf leader Paddy Ladd put it this way: “We wish for the recognition of our right to exist as a linguistic minority group . . . Labeling us as disabled demonstrates a failure to understand that we are not disabled in any way within our own community” (Dant & Gregory, 1991, p. 14). U. S. Deaf scholar Tom Humphries concurs: “There is no room within the culture of Deaf people for an ideology that all Deaf people are deficient. It simply does not compute. There is no “handicap” to overcome . . . (Humphries, 1993, p. 14). American Deaf leader MJ Bienvenu asks: “Who benefits when we attempt to work in coalition with disability groups? . . . How can we fight for official recognition of ASL and allow ourselves as “communication disordered” at the same time?” And she concludes: “We are proud of our language, culture and heritage. Disabled we are not!” (Bienvenu, 1989, p. 13).

Nevertheless, many in the disability rights movement, and even some Deaf leaders, have joined professionals in promoting the disability construction of all deafness. To defend this construction, one leading disability advocate, Vic Finkelstein, has advanced the following argument based on the views of the people directly concerned: Minorities that have been discriminated against, like blacks, would refuse an operation to eliminate what sets them apart, but this is not true for disabled people: “every (!) disabled person would welcome such an operation” (*Finkelstein’s exclamation point*). And, from this perspective, Deaf people, he maintains, “have more in common with other disability groups than they do with groups based upon race and gender” (Finkelstein, 1991, p. 265). However, in fact, American Deaf people are more like blacks in that most would refuse an operation to eliminate what sets them apart (as Dr. Rosen did on “Sixty Minutes”). One U. S. survey of Deaf adults asked if they would like an implant operation so they could hear; more than eight out of 10 declined (Evans, 1989). When the magazine *Deaf Life* queried its subscribers, 87 percent of respondents said that they did not consider themselves handicapped.

There are other indications that American Deaf culture simply does not have the ambivalence that, according to Abberley, is called for in disability: “Impairment must be identified as a bad thing, insofar as it is an undesirable consequence of a distorted social development, at the same time as it is held to be a positive attribute of the individual who is impaired” (Abberley, 1987, p. 9). American Deaf people (like their counterparts in many other nations) think cultural Deafness is a good thing and would like to see more of it. Expectant Deaf parents, like those in any other language minority, commonly hope to have Deaf children with whom they can share their language, culture and unique experiences. One Deaf mother from Los Angeles recounted to a researcher her reaction when she noticed that her baby did not react to Fourth of July fireworks: “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’ (Becker, 1980, p. 55). Likewise an expectant Deaf mother in Boston told the *Globe*, “I want my daughters to be like me, to be deaf” (Saltus, 1989, p. 27). The Deaf community, writes Paddy Ladd, “regards the birth of each and every deaf child as a precious gift” (quoted in Oliver, 1989, p. 199). Deaf and hearing scholars expressed the same view in a 1991 report to the U. S. 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 (Padden, 1990).

Finkelstein acknowledges that many Deaf people reject the label “disabled” but he attributes it to the desire of Deaf people to distance themselves from social discrimination. What is missing from the

construction of deafness is what lies at the heart of the linguistic minority construction: Deaf culture. Since people with disabilities are themselves engaged in a struggle to change the construction of disability, they surely recognize that disabilities are not “lying there in the road” but are indeed socially constructed. Why is this not applied to Deaf people? Not surprisingly, deafness is constructed differently in Deaf cultures than it is in hearing cultures.

Advocates of the disability construction for all deaf people, use the term “deaf community” to refer to all people with significant hearing impairment, on the model of “the disability community.” So the term seems to legitimate the acultural perspective on Deaf people. When Ladd (*supra*) and other advocates of the linguistic minority construction speak of the Deaf community, however, the term refers to a much smaller group with a distinct manual language, culture, and social organization.<sup>1</sup> It is instructive, as American Deaf leader Ben Bahan has suggested, to see how ASL speakers refer to their minority; one term can be glossed as DEAF-WORLD. The claim that one is in the DEAF-WORLD, or that someone else is, is not a claim about hearing status at all; it is an expression of that self-recognition or recognition of others that is defining for all ethnic collectivities (Johnson & Erting, 1989). It is predictive about social behavior (including attitudes, beliefs and values) and language, but not about hearing status. All degrees of hearing can be found among Deaf people (it is a matter of discussion whether some hearing people with Deaf parents are Deaf), and most people who are hearing-impaired are not members of the DEAF-WORLD.

In ASL the sign whose semantic field most overlaps that of the English “disability” can be glossed in English LIMP-BLIND-ETC. I have asked numerous informants to give me examples from that category: they have responded by citing (in literal translation) people in wheelchairs, blind people, mentally retarded people, and people with cerebral palsy, but no informant has ever listed DEAF and all reject it when asked. Another term in use in the Boston area (and elsewhere), which began as a fingerspelled borrowing from English, can be glossed D-A. My informants agree that Deaf is not D-A. The sign M-H-C (roughly, “multiply-handicapped”) also has some currency. When I have asked Deaf people here for examples of M-H-C, DEAF-BLIND has never been listed, and when I propose it, it is rejected.

Other important differences between culturally Deaf people and people with disabilities come to light when we consider these groups’ priorities. Among the preconditions for equal participation in society by disabled persons, the U.N. *Standard Rules* (1994) list medical care, rehabilitation, and support services such as personal assistance. “Personal assistance services are the new top of the agenda issue for the disability rights movement,” one chronicler reports (Shapiro, 1993, p. 251). From my observation, Deaf people do not attach particular importance to medical care, not place any special value on rehabilitation or personal assistance services,<sup>2</sup> not have any particular concern with autonomy and independent living. Instead, the preconditions for Deaf participation are more like those of other language minorities: culturally Deaf people campaign for acceptance of their language and its broader use in the schools, the workplace, and in public events.

Integration, in the classroom, the workforce and the community, “has become a primary goal of today’s disability movement” (Shapiro, 1993, p. 144). School integration is anathema to the DEAF-WORLD. Because most Deaf children have hearing parents, they can only acquire full language and socialization in specialized schools, in particular the prized network of residential schools; Deaf children are drowning in the mainstream (Lane, 1992). While advocates for people with disabilities recoil in horror at segregated institutions, evoking images of Willowbrook and worse, the Deaf alumni of residential schools return to their alma mater repeatedly over the years, contribute to their support, send their Deaf children to them, and vigorously protest the efforts of well-meaning but grievously ill-informed members of the disability rights movement to close those schools. These advocates fail to take account of language and culture and therefore of the difference between imposed and elective segregation. Where people with disabilities cherish independence, culturally Deaf people cherish interdependence. People with disabilities may gather for political action; Deaf people traditionally gather primarily for socializing. Deaf people marry Deaf people 90 percent of the time in the U. S. (Schein, 1989).

With the shift in the construction of disability has come an emphasis on the bonds that unite people with disabilities to the rest of society with whom they generally share not only culture but also ranges of capacities and incapacities (cf. Barton, 1993). “We try to make disability fixed and dichotomous,” writes Zola, “but it is fluid and continuous” (Zola, 1993, p. 24). More than 20 percent of the noninstitutionalized population of the U.S. has a disability, we are told, and over 7.7 million Americans report that hearing is their primary functional limitation (Dowler & Hirsch, 1994). This universalizing view, according to which most people have some disability at least some of the time, is strikingly at odds with the DEAF-WORLD, small, tightly knit, with its own language and culture, sharply demarcated from the rest of society: there is no slippery slope between Deaf and hearing. “Deaf people are foreigners,” wrote an early president of the National Association of the Deaf, “[living] among a people whose language they can never learn” (Hanson, cited in Van Cleve & Crouch, 1989, p. ix).

It is significant that the four student leaders who led the uprising known as the Gallaudet Revolution, were Deaf children of Deaf parents, deeply imbued with a sense of DEAF-WORLD, and natively fluent in ASL. One of them explained to *USA Today* the significance of the Revolution as it relates to the construction of deafness: “Hearing people sometimes call us handicapped. But most—maybe all deaf people—feel that we’re more of an ethnic group because we speak a different language . . . We also have our own culture . . . There’s more of an ethnic difference than a handicap difference between us and hearing people” (Hlibok, 1988, p. 11a). The new Deaf president of Gallaudet sought to explain the difference in the underlying construction in these terms: “More people realize now that deafness is a difference, not a deficiency” (Jordan, quoted in Gannon, 1989, p. 173).

So there is no reason to think that Paddy Ladd, Tom Humphries and MJ Bienvenu are being insincere when they claim that Deaf people are not disabled. Quite the contrary: since all are leaders of Deaf communities and are steeped in deaf culture, they advance the construction of deafness that arises from their culture. Mr. Finkelstein could have been tipped off to this very different construction by observing how various groups choose to be labeled: disability groups may find labels such as “disabled” or “motorically-impaired” or “visually handicapped” distasteful and reserve for themselves the right to call someone a “crip,” but Deaf culture embraces the label “Deaf” and asks that everyone use it, as in The National Association of the Deaf and The World Federation of the Deaf. It seems right to speak of “the Deaf” as we speak of “The French” or “The British.” It is alien to Deaf culture on two counts to speak of its members as “people with hearing-impairment.” First, it is the troubled-persons industry for deafness that invented and promoted the label in English “hearing-impaired” (Ross & Calvert, 1967; Wilson *et al.*, 1974; Castle, 1990). Second, the “people with” construction implies that the trait is incidental rather than defining, but one’s culture is never an incidental trait. It seems to be an error in ordinary language to say, “I happen to be Hispanic,” or “I happen to be Deaf”; who would you be, after all, if you were you and yet not Hispanic, or not Deaf? But it is acceptable to say, “I happen to have a spinal cord injury.”

Deaf cultures do not exist in a vacuum. Deaf Americans embrace many cultural values, attitudes, beliefs and behaviors that are part of the larger American culture and, in some instances, that are part of ethnic minority cultures such as African-American, Hispanic-American, etc. Because hearing people have obliged Deaf people to interact with the larger hearing society in terms of a disability model, that model has left its mark on Deaf culture. In particular, Deaf people frequently have found themselves recipients of unwanted special services provided by hearing people. “In terms of its economic, political and social relations to hearing society, the Deaf minority can be viewed as a colony” (Markowicz & Woodward, 1978, p. 33). As with colonized peoples, some Deaf people have internalized the “other’s” (disability) construction of them alongside their own cultural construction (Lane, 1992). For example, they may be active in their Deaf club and yet denigrate skilled use of ASL as “low sign”; “high sign” is a contact variety of ASL that is closer to English-language word order. The Deaf person who uses a variety of ASL marked as English frequently has greater access to wider resources such as education and employment. Knowing when to use which variety is an important part of being Deaf (Johnson



& Erting, 1989). Granted that culturally Deaf people must take account of the disability model of deafness, that they sometimes internalize it, and that it leaves its mark on their culture, all this does not legitimize that model—any more than granting that African-Americans had to take account of the construction of the slave as property, sometimes internalized that construction, and found their culture marked by it legitimizes that construction of their ethnic group.

Neither culturally Deaf people nor people with disabilities are a homogeneous group.<sup>3</sup> Many of the differences between the two that I have cited will not apply to particular subgroups or individuals; nevertheless, it should be clear that cultural Deafness involves a constellation of traits quite different from those of any disability group. Faced with these salient differences, those who would argue that Deaf people are “really” disabled, sometimes resort instead to arguing that they are “really not” like linguistic minorities (Fishman, 1982). Certainly there are differences. For example, Deaf people cannot learn English as a second language as easily as other minorities. Second and third generation Deaf children find learning English no easier than their forbears, but second and third generation immigrants to the U. S. frequently learn English before entering school. The language of the DEAF-WORLD is not usually passed on from generation to generation; instead, it is commonly transmitted by peers or associates. Normally, Deaf people are not proficient in this native language until they reach school age. Deaf people are more scattered geographically than many linguistic minorities. The availability of interpreters is even more vital for Deaf people than for many other linguistic minorities because there are so few Deaf lawyers, doctors and accountants, etc. Few Deaf people are in high-status public positions in our society (in contrast with, say, Hispanics), and this has hindered the legitimation of ASL use (Kyle, 1990, 1991; Parratt & Tipping, 1991). However, many, perhaps all, linguistic minorities have significant features that differentiate them: Members of the Chinese-American community are increasingly marrying outside their linguistic minority but this is rare for ASL speakers. Many Native American languages are dying out or have disappeared; this is not true of ASL which is unlikely ever to die out. Spanish-speaking Americans are so diverse a group that it may not be appropriate to speak of the Hispanic community in the U. S. (Wright, 1994). Neither the newer strategy of citing what is special about the ASL-speaking minority nor the older one of minimizing ASL itself hold much promise of discrediting the construction of deafness as linguistic minority.

It is undeniable that culturally Deaf people have great common cause with people with disabilities. Both pay the price of social stigma. Both struggle with the troubled-persons industries for control of their destiny. Both endeavor to promote their construction of their identity in competition with the interested (and generally better funded) efforts of professionals to promote *their* constructions. And Deaf people have special reasons for solidarity with people with hearing impairments; 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 special identity to be subsumed under the construct of disability they set themselves up for wrong solutions and bitter disappointments.

It is because disability advocates think of Deaf children as disabled that they want to close the special schools and absurdly plunge Deaf children into hearing classrooms in a totally exclusionary program called inclusion. It is because government is allowed to proceed with a disability construction of cultural Deafness that the U. S. Office of Bilingual Education and Minority Language Affairs has refused for decades to provide special resources for schools with large numbers of ASL-using children although the law requires it to do so for children using any other non-English language. It is because of the disability construction that court rulings requiring that children who do not speak English receive instruction initially in their best language have not been applied to ASL-using children. It is because of the disability construction that the teachers most able to communicate with Britain's Deaf children are excluded from the profession on the pretext that they have a disqualifying disability. It is because lawmakers have been encouraged to believe by some disability advocates and prominent deaf figures that Deaf people are disabled that, in response to the Gallaudet Revolution, the U. S. Congress

passed a law, not recognizing ASL or the DEAF-WORLD as a minority, but a law establishing another institute of *health*, The National Institute on Deafness and Other Communications Disorders [*sic*], operated by the deafness troubled persons industry, and sponsoring research to reduce hereditary deafness. It is because of the disability construction that organizations *for* the Deaf (e.g., the Royal National Institute for the Deaf) are vastly better funded by government than organizations *of* the Deaf (e.g., the British Deaf Association).

One would think that people with disabilities might be the first to grasp and sympathize with the claims of Deaf people that they are victims of a mistaken identity. People with disabilities should no more resist the self-construction of culturally Deaf people, than Deaf people should subscribe to a view of people with disabilities as tragic victims of an inherent flaw.

## Changing to the Linguistic Minority Construction

Suppose our society were generally to adopt a disability construction of deafness for most late-deafened children and adults and a linguistic minority construction of Deaf people for most others, how would things change? The admirable Open University course, *Issues in Deafness* (1991) prompted these speculations.

(1) Changing the construction changes the legitimate authority concerning the social problem. In many areas, such as schooling, the authority would become Deaf adults, linguists and sociologists, among others. There would be many more service providers from the minority: Deaf teachers, foster and adoptive parents, information officers, social workers, advocates. Non-Deaf service providers would be expected to know the language, history, and culture of the Deaf linguistic minority.

(2) Changing the construction changes how behavior is construed. Deaf people would be expected to use ASL (in the U. S.) and to have interpreters available; poor speech would be seen as inappropriate.

(3) Changing the construction may change the legal status of the social problem group. Most Deaf people would no longer claim disability benefits or services under the present legislation for disabled people. The services to which the Deaf linguistic minority has a right in order to obtain equal treatment under the law would be provided by other legislation and bureaucracies. Deaf people would receive greater protection against employment discrimination under civil rights laws and rulings. Where there are special provisions to assist the education of linguistic minority children, Deaf children would be eligible.

(4) Changing the construction changes the arena where identification and labeling take place. In the disability construction, deafness is medicalized and labeled in the audiologist's clinic. In the construction as linguistic minority, deafness is viewed as a social variety and would be labeled in the peer group.

(5) Changing the construction changes the kinds of intervention. The Deaf child would not be operated on for deafness but brought together with other Deaf children and adults. The disability construction orients hearing parents to the question, what can be done to mitigate my child's impairment? The linguistic minority construction presents them with the challenge of insuring that their child has language and role models from the minority (Hawcroft, 1991).

## Obstacles to Change

The obstacles to replacing a disability construction of deafness for much of the concerned population with a linguistic minority construction are daunting. In the first place, people who have little familiarity with deafness find the disability construction self-evident and the minority construction

elusive. As I argue in *The Mask of Benevolence* (Lane, 1992), hearing people led to reflect on deafness generally begin by imagining themselves without hearing—which is, of course, to have a disability but not to be Deaf. Legislators can easily grasp the disability construction, not so the linguistic minority construction. The same tendency to uncritically accept the disability model led *Sixty Minutes* to feature a child from among the nine percent of childhood implant candidates who were deafened after learning English rather than from the 91 percent who do not identify with the English-speaking majority (Allen *et al.*, 1994). Not only did the interviewer find the disability construction of deafness easier to grasp but no doubt the producers thought their millions of viewers would do likewise. Social problems are a favorite theme of the media but they are almost always presented as private troubles—deafness is no exception—because it makes for more entertaining viewing.

The troubled-persons industry associated with deafness—the “audist establishment” (Lane, 1992)—vigorously resists efforts to replace their construction of deafness. Audist policy is that ASL is a kind of primitive prosthesis, a way around the communication impasse caused by deaf peoples’ disability. The audists control teacher training programs, university research facilities, the process of peer review for federal grant monies, the presentations made at professional meetings, and publications in professional journals; they control promotion and through promotion, salary. They have privileged access to the media and to law-making bodies when deafness is at issue. Although they lack the credibility of Deaf people themselves, they have expert credentials and they are fluent in speaking and writing English so law and policy makers and the media find it easier to consult them.

When a troubled-persons industry recasts social problems as private troubles it can treat, it is protecting its construction by removing the appearance of a social issue on which there might be political disagreement. The World Health Organization, for example, has medicalized and individualized what is social; services are based on an individualized view of disability and are designed by professionals in the disability industry (Oliver, 1991). The U. S. National Institute on Deafness and Other Communications Disorders proclaims in its very title the disability construction of deafness that it seeks to promote. The American Speech-Language Hearing Association, for example, has the power of accrediting graduate programs for training professionals who work with Deaf people; a program that deviated too far from the disability construction could lose its accreditation; without accreditation its students would not be certified; without the promise of certification, no one would enter the training program.

Some of the gravest obstacles to broader acceptance of the linguistic minority model come from members of the minority itself. Many members of the minority were socialized in part by professionals (and parents) to adopt a disabled role. Some Deaf people openly embrace the disability construction and thus undercut the efforts of other Deaf people to discredit it. Worse yet, many opportunities are provided to Deaf people (e.g., access to interpreters) on the condition that they adopt the alien disability construction. This double blind—accept our construction of your life or give up your access to equal citizenship—is a powerful form of oppression. Thus, many members of the DEAF-WORLD endorsed the Americans with Disabilities Act with its provisions for deaf people, all the while believing they are not disabled but lending credence to the claim that they are. In a related double blind, Deaf adults who want to become part of the professions serving Deaf people, find that they must subscribe to audist views of rehabilitation, special education, etc.

Exponents of the linguistic minority construction are at a further disadvantage because there is little built-in cultural transmission of their beliefs. The most persuasive advocates for Deaf children, their parents, must be taught generation after generation the counter-intuitive linguistic minority construction because most are neither Deaf themselves nor did they have Deaf parents.

A further obstacle arising within the DEAF-WORLD to promoting the linguistic minority construction concerns, ironically, the form that much Deaf political activism takes. Ever since the first congresses of Deaf people organized in response to the Congress of Milan in 1880, Deaf leaders have appeared before friendly Deaf audiences to express their outrage—to preach to the converted. Written

documents—position papers, articles and proceedings—have similarly been addressed to and read by primarily the DEAF-WORLD. It is entirely natural to prefer audiences with whom one shares language and culture, the more so as Deaf people have rarely been permitted to address audiences comprised of hearing professionals. Admittedly, preaching to the converted has value—it may evoke fresh ideas and it builds solidarity and commitment. Advocates of the disability construction do the same; childhood implant conferences, for example, rigorously exclude the voices of the cautious or frankly opposed.

I hope it may be allowed, however, to someone who has been invited to address numerous Deaf audiences and is exasperated by the slow pace of reform to point out that too much of this is an obstacle to true reform because it requires effort, permits the illusion that significant action has been taken, and yet changes little since Deaf people themselves are not responsible for the spread of the disability construction and have little direct power to change its range of application. What part of the battle is won when a Deaf leader receives a standing ovation from a Deaf audience? In the tradition of Deaf activism during the International Congress on the Education of the Deaf in Manchester in 1985, and during the Gallaudet Revolution, the past year have seen a striking increase in Europe of Deaf groups turning outward and presenting their views to hearing people and the media uninvited, particularly in opposition to cochlear implant surgery on Deaf children (Lane, 1994).

## Production Change

Despite all the obstacles, there are powerful social forces to assist the efforts of the DEAF-WORLD to promote the linguistic minority construction. The body of knowledge developed in linguistics, history, sociology, and anthropology (to mention just four disciplines) concerning Deaf communities has influenced Deaf leadership, bureaucratic decision-making, and legislation. The civil rights movement has given great impetus to the belief that minorities should define themselves and that minority leaders should have a significant say in the conduct of minority affairs. Moreover, the failure of the present predominant disability construction to deliver more able deaf children is a source of professional and public embarrassment and promotes change. Then, too, Deaf children of Deaf parents are frequently insulated against the disability construction to a degree by their early language and cultural acquisition within the DEAF-WORLD. These native ASL-users have important allies in the DEAF-WORLD, among hearing children of Deaf parents, and among disaffected hearing professionals. The Gallaudet Revolution did not change the disability construction on a large scale but it led to inroads against it. Growing numbers of schools, for example, are turning to the linguistic minority construction to guide their planning, curricula, teacher selection and training.

Numerous organizations have committed extensive effort and money to promoting the disability construction. What can the national associations of the Deaf do to promote the linguistic minority construction? Publications like the British Deaf Association *News* or the National Association of the Deaf *Deaf American* are an important step because they provide a forum for national political discussion. However, the discussion has lacked focus. In addition to a forum, such associations need an explicit political agenda and a plan for implementing it. Such an agenda might include, illustratively, building a greater awareness of the difference between hearing-impairment and cultural Deafness; greater acceptance of the national sign language; removal or reduction of language barriers; improving culturally sensitive health care. Nowhere I know of are such agendas made explicit—given priorities, implementation, a time plan. If these were published they could provide the needed focus for the debate. Commentary on the agenda and plan would be invited as well as rebuttals to the commentaries in subsequent issues. Such agendas, plans and debates are buttressed by scholarship. An important resource to develop is a graduate program in public administration or political science focused on the DEAF-WORLD and the promotion of the linguistic minority construction.

## Notes

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1. Padden (1980) makes a distinction between a deaf community, a group of Deaf and hearing individuals who work to achieve certain goals, and a Deaf culture, to which Deaf members of that community belong.
2. In an effort to retain the disability construction of deafness, it has been suggested that sign language interpreters should be viewed as personal assistants. However, the services of these highly trained professionals are frequently not personal but provided to large audiences and they “assist” hearing people as well as, and at the same time as, Deaf people. Nor is interpreting between any other two languages (for example, at the United Nations) considered personal assistance.
3. I am not contending that there is a unitary homogenous DEAF-WORLD. My claims about Deaf culture are best taken as hypotheses for further verification, all the more as I am not a member of the DEAF-WORLD. My means of arriving at cultural principles are the usual ones for an outsider: encounters, ASL language and literature (including stories, legends, anecdotes, poetry, plays, humor, rituals, sign play), magazines and newspaper stories, films, histories, informants, scholarly studies, and the search for principles of coherence. See Stokoe (1994) and Kyle (1990).

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# 7

## Abortion and Disability

### Who Should and Who Should Not Inhabit the World?

Ruth Hubbard

Political agitation and education during the past few decades have made most people aware of what constitutes discrimination against blacks and other racial and ethnic minorities and against women. And legal and social measures have been enacted to begin to counter such discrimination. Where people with disabilities are concerned, our level of awareness is low, and the measures that exist are enforced haphazardly. Yet people with disabilities and disability-rights advocates have stressed again and again that it is often far easier to cope with the physical aspects of a disability than with the discrimination and oppression they encounter because of it (Asch, 1988; Asch and Fine, 1988). People shun persons who have disabilities and isolate them so they will not have to see them. They fear them as though the disability were contagious. And it is, in the sense that it forces us to face our own vulnerability.

Most of us would be horrified if a scientist offered to develop a test to diagnose skin color prenatally so as to enable racially mixed people (which means essentially everyone who is considered black and many of those considered white in the Americas) to have light-skinned children. And if the scientist explained that because it is difficult to grow up black in America, he or she wanted to spare people suffering because of the color of their skin, we would counter that it is irresponsible to use scientific means to reinforce racial prejudices. Yet we see nothing wrong, and indeed hail as progress, tests that enable us to try to avoid having children who have disabilities or are said to have a tendency to acquire a specific disease or disability later in life.

The scientists and physicians who develop and implement these tests believe they are reducing human suffering. This justification seems more appropriate for speed limits, seat-belt laws, and laws to further occupational safety and health than for tests to avoid the existence of certain kinds of people. When it comes to women or to racial or ethnic groups, we insist that it is discriminatory to judge individuals on the basis of their group affiliation. But we lump people with disabilities as though all disabilities were the same and always devastating and as though all people who have one were alike.

Health and physical prowess are poor criteria of human worth. Many of us know people with a disease or disability whom we value highly and so-called healthy people whom we could readily do without. It is fortunate for human variety and variability that most of us are not called on to make such judgments, much less to implement them.

It is not new for people to view disability as a form of pollution, evidence of sin. Disability has been considered divine punishment or, alternatively, the result of witches' spells. In our scientific and medical era we look to heredity for explanations unless there is an obvious external cause, such as an accident or infectious disease. Nowadays, even if an infection can explain the disability, scientists have begun to suggest that our genes might have made us unusually susceptible to it.

In a sense, hereditary disabilities are contagious because they can be passed from one generation to the next. For this reason, well before there was a science of genetics, scientists proposed eugenic measures to stem the perpetuation of "defects."

## The Rise of Eugenics in Britain and the United States

Eugenics met its apotheosis under the Nazis, which is why many Germans oppose genetic testing and gene therapy and their use is being hotly debated in the parliament. Germans tend to understand better than people in other countries what can happen when the concern that people with disabilities will become social and economic burdens or that they will lead to a deterioration of the race begins to dictate so-called preventive health policies. They are aware that scientists and physicians were the ones who developed the Nazi policies of “selection and eradication” (*Auslese und Ausmerze*) and who oversaw their execution. What happened under the Nazis has been largely misrepresented and misinterpreted in this country, as well as among Nazi apologists in Germany. To make what happened clearer, I shall briefly review the scientific underpinnings of the Nazi extermination program, which are obscured when these practices are treated as though they were incomprehensible aberrations without historical roots or meaning—a holocaust.

German eugenics, the attempt to improve the German race, or *Volk*, by ridding it of inferior and foreign elements, was based on arguments and policies developed largely in Great Britain and the United States during the latter part of the nineteenth and the beginning of the twentieth centuries. (In what follows I shall not translate the German word *Volk* because it has no English equivalent. The closest is “people,” singular, used as a collective noun, as in “the German people *is* patriotic.” But “people,” singular, does not convey the collectivity of *Volk* because to us “people” means individuals. Therefore, we would ordinarily phrase my example, “the German people *are* patriotic.”)

The term *eugenics* is derived from the Greek word for “well born.” It was coined in 1883 by Francis Galton, cousin of Charles Darwin, as “a brief word to express the science of improving the stock, which is by no means confined to questions of judicious mating, but which, especially in the case of man [*sic*], takes cognizance of all the influences that tend in however remote a degree to give the more suitable races or strains of blood a better chance of prevailing speedily over the less suitable than they otherwise would have had” (pp. 24–25). Galton later helped found the English Eugenics Education Society and eventually became its honorary president.

British eugenics counted among its supporters many distinguished biologists and social scientists. Even as late as 1941, while the Nazis were implementing their eugenic extermination program, the distinguished biologist Julian Huxley (1941)—brother of Aldous—opened a semipopular article entitled “The Vital Importance of Eugenics” with the words: “Eugenics is running the usual course of many new ideas. It has ceased to be regarded as a fad, is now receiving serious study, and in the near future, will be regarded as an urgent practical problem.” In the article, he argues that it is crucial for society “to ensure that mental defectives [*sic*] shall not have children” and defines as mentally defective “someone with such a feeble mind that he cannot support himself or look after himself unaided.” (Notice the mix of eugenics and economics.) He says that he refuses to enter into the argument over whether such “racial degeneration” should be forestalled by “prohibition of marriage” or “segregation in institutions” combined with “sterilization for those who are at large.” He states as fact that most “mental defects” are hereditary and suggests that it would therefore be better if one could “discover how to diagnose the carriers of the defect” who are “apparently normal.” “If these could but be detected, and then discouraged or *prevented* from reproducing, mental defects could very speedily be reduced to negligible proportions among our population” (my emphasis). It is shocking that at a time when the Nazi program of eugenic sterilization and euthanasia was in full force across the Channel, Huxley expressed regret that it was “at the moment very difficult to envisage methods for putting even a limited constructive program [of eugenics] into effect” and complained that “that is due as much to difficulties in our present socioeconomic organization as to our ignorance of human heredity, and most of all to the absence of a eugenic sense in the public at large.”

The American eugenics movement built on Galton and attained its greatest influence between 1905 and 1935. An underlying concern of the eugenicists is expressed in a statement by Lewis Terman (1924), one of the chief engineers of I.Q. testing: “The fecundity of the family stocks from which our



most gifted children come appears to be definitely on the wane. . . . It has been figured that if the present differential birth rate continues 1,000 Harvard graduates will, at the end of 200 years, have but 56 descendants, while in the same period, 1,000 S. Italians will have multiplied to 100,000." To cope with this dire eventuality, eugenics programs had two prongs: "positive eugenics"—encouraging the "fit" (read "well-to-do") to have lots of children—and "negative eugenics"—preventing the "unfit" (defined to include people suffering from so-called insanity, epilepsy, alcoholism, pauperism, criminality, sexual perversion, drug abuse, and especially feeble-mindedness) from having any.

Many distinguished American geneticists supported eugenics, but none was more active in promoting it than Charles Davenport, who, after holding faculty appointments at Harvard and the University of Chicago, in 1904 became director of the "station for the experimental study of evolution," which he persuaded the Carnegie Institution of Washington to set up in Cold Spring Harbor on Long Island. His goal was to collect large amounts of data on human inheritance and store them in a central office. In 1910, he managed to persuade the heiress to the Harriman railroad fortune to fund the Eugenics Record Office at Cold Spring Harbor, for which he got additional money from John D. Rockefeller, Jr. He appointed Harry W. Laughlin, a Princeton Ph. D., as superintendent and recruited a staff of young graduates from Radcliffe, Vassar, Cornell, Harvard, and other elite institutions as fieldworkers to accumulate interview data about a large number of so-called mental and social defectives. The office and its staff became major resources for promoting the two legislative programs that formed the backbone of U. S. eugenics: involuntary-sterilization laws and the Immigration Restriction Act of 1924.

The first sterilization law was enacted in Indiana in 1907, and by 1931 some thirty states had compulsory-sterilization laws on their books. Aimed in general at the insane and "feeble-minded" (broadly interpreted to include many recent immigrants and other people who did badly on I.Q. tests because they were functionally illiterate or barely spoke English), these laws often extended to so-called sexual perverts, drug fiends, drunkards, epileptics, and "other diseased and degenerate persons" (Ludmerer, 1972). Although most of these laws were not enforced, by January 1935 some twenty thousand people in the United States had been forcibly sterilized, nearly half of them in California. Indeed, the California law was not repealed until 1980 and eugenic-sterilization laws are still on the books in about twenty states.

The eugenic intent of the Immigration Restriction Act of 1924 was equally explicit. It was designed to decrease the proportion of poor immigrants from southern and eastern Europe so as to give predominance to Americans of British and north European descent. This goal was accomplished by restricting the number of immigrants allowed into the United States from any one country in each calendar year to at most 2 percent of U.S. residents who had been born in that country as listed in the Census of 1890 (so, thirty-four years earlier). The date 1890 was chosen because it established as a baseline the ethnic composition of the U.S. population prior to the major immigrations from eastern and southern Europe, which began in the 1890s. Laughlin of the Eugenics Record Office was one of the most important lobbyists and witnesses at the Congressional hearings that preceded passage of the Immigration Restriction Act and was appointed "expert eugenical agent" of the House Committee on Immigration and Naturalization (Kevles, 1985).

## Racial Hygiene in Germany

What was called eugenics in the United States and Britain came to be known as racial hygiene in Germany. It was the response to several related and widely held beliefs: (1) that humane care for people with disabilities would enfeeble the "race" because they would survive to pass their disabilities on to their children; (2) that not just mental and physical diseases and so-called defects, but also poverty, criminality, alcoholism, prostitution, and other social problems were based in biology and inherited; and (3) that genetically inferior people were reproducing faster than superior people and would eventually displace them. Although these beliefs were not based in fact, they fueled racist thinking and social programs in Britain and the United States as well as in Germany.

German racial hygiene was founded in 1895, some dozen years after Galton's eugenics, by a physician, Alfred Plötz, and was based on much the same analysis of social problems as the British and American eugenics movements were. In 1924, Plötz started the *Archive of Race- and Socio-biology* (*Archiv für Rassen- und Gesellschaftsbiologie*) and the next year helped found the Society for Racial Hygiene (Gesellschaft für Rassenhygiene). German racial hygiene initially did not concern itself with preventing the admixture of "inferior" races, such as Jews or gypsies, in contrast to the British and American movements where miscegenation with blacks, Asians, Native Americans, and immigrants of almost any sort was one of the major concerns. The recommended means for preventing racial degeneration in Germany, as elsewhere, was sterilization. Around 1930 even some German socialists and communists supported the eugenic sterilization of inmates of psychiatric institutions, although the main impetus came from the Nazis. The active melding of anti-Semitism and racial hygiene in Germany began during World War I and accelerated during the 1920s, partly in response to economic pressures and a scarcity of available positions, which resulted in severe competition for jobs and incomes among scientists and physicians, many of whom were Jews.

Racial hygiene was established as an academic discipline in 1923, when Fritz Lenz, a physician and geneticist, was appointed to the newly created Chair of Racial Hygiene at the University of Munich, a position he kept until 1933, when he moved to the Chair of Racial Hygiene at the University of Berlin. Lenz, Eugen Fischer, and Erwin Baer coauthored the most important textbook on genetics and racial hygiene in German. Published in 1921, it was hailed in a review in the *American Journal of Heredity* in 1928 as "the standard textbook of human genetics" in the world (quoted in Proctor, 1988, p. 58). In 1931, it was translated into English, and the translation was favorably reviewed in Britain and the United States despite its blatant racism, or perhaps because of it. By 1933, eugenics and racial hygiene were being taught in most medical schools in Germany.

Therefore the academic infrastructure was in place when the Nazis came to power and began to build a society that gave biologists, anthropologists, and physicians the opportunity to put their racist and eugenic theories into practice. Looking back on this period, Eugen Fischer, who directed the Kaiser Wilhelm Institute for Anthropology, Human Genetics, and Eugenics in Berlin from 1927 to 1942, wrote in a newspaper article in 1943: "It is special and rare good luck when research of an intrinsically theoretical nature falls into a time when the general world view appreciates and welcomes it and, what is more, when its practical results are immediately accepted as the basis for governmental procedures" (quoted in Müller-Hill, 1984, p. 64; my translation). It is not true, as has sometimes been claimed, that German scientists were perverted by Nazi racism. Robert Proctor (1988) points out that "it was largely medical scientists who *invented* racial hygiene in the first place" (p. 38; original emphasis).

A eugenic-sterilization law, drafted along the lines of a "Model Sterilization Law" published by Laughlin (the superintendent of Davenport's Eugenics Record Office at Cold Spring Harbor), was being considered in 1932 by the Weimar government. On July 14, 1933, barely six months after Hitler took over, the Nazi government passed its eugenic-sterilization law. This law established genetic health courts (*Erbgesundheitsgerichte*), presided over by a lawyer and two physicians, one of whom was to be an expert on "hereditary pathology" (*Erbpathologie*), whose rulings could be appealed to similarly constituted supreme genetic health courts. However, during the entire Nazi period only about 3 percent of lower-court decisions were reversed. The genetic health courts could order the sterilization of people on grounds that they had a "genetically determined" disease, such as "inborn feeble-mindedness, schizophrenia, manic-depressive insanity, hereditary epilepsy, Huntington's disease, hereditary blindness, hereditary deafness, severe physical malformations, and severe alcoholism" (Müller-Hill, 1984, p. 32; my translation). The law was probably written by Dr. Ernst Rüdin, professor of psychiatry and director of the Kaiser Wilhelm Institute for Genealogy and Demography of the German Research Institute for Psychiatry in Munich. The official commentary and interpretation of the law was published under his name and those of an official of the Ministry of the Interior, also a medical doctor, and of a representative of the Health Ministry in the Department of the Interior who was a doctor of laws. All practicing physicians were sent copies of the law and commentaries describing the acceptable procedures for sterilization and castration.

The intent of the law was eugenic, not punitive. Physicians were expected to report patients and their close relatives to the nearest local health court and were fined if they failed to report someone with a so-called hereditary disease. Although some physicians raised the objection that this requirement invaded the doctor-patient relationship, the health authorities argued that this obligation to notify then was no different from requirements that physicians report the incidence of specific infectious diseases or births and deaths. The eugenic measures were to be regarded as health measures pure and simple. And this is the crucial point: the people who designed these policies and the later policies of euthanasia and mass extermination as well as those who oversaw their execution looked on them as sanitary measures, required in this case to cure not individual patients but the collective—the *Volk*—of threats to its health (Lifton, 1987; Proctor, 1988).

As early as 1934, Professor Otmar von Verschuer, then dean of the University of Frankfurt and director of its Institute for Genetics and Racial Hygiene and later the successor of Fischer as director of the Kaiser Wilhelm Institute for Anthropology, Human Genetics, and Eugenics in Berlin, urged that patients should not be looked on, and treated, as individuals. Rather the patient is but “one part of a much larger whole or unity: of his family, his race, his *Volk*” (quoted in Proctor, 1988, p. 105). Minister of the Interior Wilhelm Frisch estimated that at least half a million Germans had genetic diseases, but some experts thought that the true figure was more like one in five, which would be equivalent to thirteen million. In any event, by 1939 some three to four hundred thousand people had been sterilized, with a mortality of about 0.5 percent (Proctor, 1988, pp. 108–109). After that there were few individual sterilizations. Later, large numbers of people were sterilized in the concentration camps, but that was done without benefit of health courts, as part of the program of human experimentation.

The eugenic-sterilization law of 1933 did not provide for sterilization on racial grounds. Nonetheless, in 1937 about five hundred racially mixed children were sterilized; the children had been fathered by black French colonial troops brought to Europe from Africa after World War I to occupy the Rhineland (the so-called Rheinlandbastarde).

The first racist eugenic measures were passed in 1935. They were the Nürnberg antimiscegenation, or blood-protection laws, which forbade intermarriage or sexual relations between Jews and non-Jews and forbade Jews from employing non-Jews in their homes. The Nürnberg laws also included a “Law for the Protection of the Genetic Health of the German People,” which required premarital medical examinations to detect “racial damage” and required people who were judged “damaged” to marry only others like themselves, provided they first submitted to sterilization. The Nürnberg laws were considered health laws, and physicians were enlisted to enforce them. So-called positive eugenics was practiced by encouraging “genetically healthy” German women to have as many children as possible. They were persuaded to do so by means of propaganda, economic incentives, breeding camps, and strict enforcement of the law forbidding abortion except for eugenic reasons (Koonz, 1987).

The next stage in the campaign of “selection and eradication” was opened at the Nazi party congress in 1935, where plans were made for the “destruction of lives not worth living.” The phrase was borrowed from the title of a book published much earlier, in 1920, by Alfred Hoche, professor of psychiatry and director of the Psychiatric Clinic at Freiburg, and Rudolf Binding, professor of jurisprudence at the University of Leipzig. In their book, entitled *The Release for Destruction of Lives Not Worth Living (Die Freigabe zur Vernichtung lebensunwerten Lebens)*, these professors argued for killing “worthless” people, whom they defined as those who are “mentally completely dead” and those who constitute “a foreign body in human society” (quoted in Chorover, 1979, p. 97). At the time the program was initiated, the arguments focused on the money wasted in keeping institutionalized (hence “worthless”) people alive, for in the early stages the rationale of the euthanasia campaign was economic as much as eugenic. Therefore the extermination campaign was directed primarily at inmates of state psychiatric hospitals and children living in state institutions for the mentally and physically disabled. Jews were specifically excluded because they were not considered worthy of euthanasia. (Here, too, the Nazis were not alone. In 1942, as the last inmates of German mental hospitals were being finished off, Dr. Foster Kennedy, an American psychiatrist writing in the official publication of the American

Psychiatric Association, advocated killing mentally retarded children of five and older (Proctor, 1988). The arguments were phrased in humane terms like these: "Parents who have seen the difficult life of a crippled or feebleminded child must be convinced that though they have the moral obligation to care for the unfortunate creatures, the wider public should not be obliged . . . to assume the enormous costs that long-term institutionalization might entail" (quoted in Proctor, 1988, p. 183). This argument calls to mind the statement by Bentley Glass (1971) about parents not having "a right to burden society with a malformed or a mentally incompetent child."

In Germany, the propaganda was subtle and widespread. For example, Proctor (1988, p. 184) cites practice problems in a high school mathematics text published for the school year 1935–36, in which students were asked to calculate the costs to the Reich of maintaining mentally ill people in various kinds of institutions for different lengths of time and to compare the costs of constructing insane asylums and housing units. How is that for relevance?

Although the euthanasia program was planned in the mid-1930s, it was not implemented until 1939, when wartime dislocation and secrecy made it relatively easy to institute such extreme measures. Two weeks before the invasion of Poland an advisory committee commissioned by Hitler issued a secret report recommending that children born with Down syndrome, microcephaly, and various deformities be registered with the Ministry of the Interior. Euthanasia, like sterilization, was to proceed with the trappings of selection. Therefore physicians were asked to fill out questionnaires about all children in their care up to age three who had any of these kinds of disabilities. The completed questionnaires were sent to three-man committees of medical experts charged with marking each form "plus" or "minus." Although none of these "experts" ever saw the children, those whose forms were marked "plus" were transferred to one of a number of institutions where they were killed. Some of the oldest and most respected hospitals in Germany served as such extermination centers. By 1941 the program was expanded to include older children with disabilities and by 1943, to include healthy Jewish children. Also in 1939, evaluation forms were sent to psychiatric institutions for adults for selection and so-called euthanasia.

By September 1941 over seventy thousand inmates had been killed at some of the most distinguished psychiatric hospitals in Germany, which had been equipped for this purpose with gas chambers, disguised as showers, and with crematoria (Lifton, 1986; Proctor, 1988). (When the mass extermination of Jews and other "undesirables" began shortly thereafter, these gas chambers were shipped east and installed at Auschwitz and other extermination camps.) Most patients were gassed or killed by injection with legal drugs, but a few physicians were reluctant to intervene so actively and let children die of slow starvation and the infectious diseases to which they became susceptible, referring to this as death from "natural" causes. Relatives were notified that their family member had died suddenly of one of a number of infectious diseases and that the body had been cremated for reasons of public health. Nevertheless, rumors began to circulate, and by 1941 hospital killings virtually ceased because of protests, especially from the Church.

There is a direct link between this campaign of "selection and eradication" and the subsequent genocide of Jews, gypsies, communists, homosexuals, and other "undesirables." Early on these people were described as "diseased" and their presence, as an infection or a cancer in the body of the *Volk*. Proctor (1988, p. 194) calls this rationalization "the medicalization of antisemitism." The point is that the Nazi leaders shouted anti-Semitic and racist propaganda from their platforms, but when it came to devising the measures for ridding the Thousand Year Reich of Jews, gypsies, and the other undesirables, the task was shouldered by the scientists and physicians who had earlier devised the sterilization and euthanasia programs for the mentally or physically disabled. Therefore, nothing came easier than a medical metaphor: Jews as cancer, Jews as disease. And so the Nazi extermination program was viewed by its perpetrators as a gigantic program in sanitation and public health. It started with quarantining the offending organisms in ghettos and concentration camps and ended with the extermination of those who did not succumb to the "natural" consequences of the quarantine, such as the various epidemics and hunger.

Yet a measure of selection was practiced throughout the eradication process: It was still *Auslese* as well as *Ausmerze*. At every step choices were made of who could still be used and who had become “worthless.” We have read the books and seen the films that show selections being made as the cattle cars emptied the victims into the concentration camps: to work or to die? That is where Joseph Mengele, an M. D./Ph. D., selected the twins and other unfortunates to use as subjects for his scientific experiments at Auschwitz, performed in collaboration with Professor von Verschuer, at that time director of the Kaiser Wilhelm Institute for Anthropology, Human Genetics, and Eugenics in Berlin. And von Verschuer was not the only distinguished scientist who gratefully accepted the human tissues and body fluids provided by Mengele. After the war it became fashionable to characterize the experiments as “bad science,” but as Beno Müller-Hill (1984) emphasizes, nothing about them would be considered “bad” were they done with mice. What was “bad” was not their scientific content but the fact that they were being done with “disenfranchised human beings” (p. 97).

#### Prenatal Testing: Who Should Inhabit the World?

I want to come back to the present, but I needed to go over this history in order to put my misgivings and those of some of the Germans who are opposing genetic testing into the proper perspective. I can phrase the problem best by rephrasing a question Hannah Arendt asks in the epilogue of her commentary on the trial of Adolf Eichmann. Who has the “right to determine who should and who should not inhabit the world?” (1977). That’s what it comes down to.

So let me be clear: I am not suggesting that prenatal diagnosis followed by abortion is similar to euthanasia. Fetuses are not people. And a woman must have the right to terminate her pregnancy, whatever her reasons. I am also not drawing an analogy between what the Nazis did and what we and others in many of the industrialized countries are doing now. Because the circumstances are different, different things are being done and for different reasons. But a similar eugenic ideology underlies what happened then and the techniques now being developed. So it is important that we understand how what happened then came about—and not in some faraway culture that is altogether different from ours but in the heart of Europe, in a country that has produced artists, writers, composers, philosophers, jurists, scientists, and physicians the equal of any in the Western world. Given that record, we cannot afford to be complacent.

Scientists and physicians in this and other countries are once more engaged in developing the means to decide what lives are worth living and who should and should not inhabit the world. Except that now they provide only the tools, while pregnant women themselves have to make the decisions, euphemistically called choices. No one is forced to do anything. A pregnant woman must merely “choose” whether to terminate a wanted pregnancy because she has been informed that her future child will have a disability (although, as I have said before, usually no one can tell her how severe the disability will be). If she “chooses” not to take the tests or not to terminate a pregnancy despite a positive result, she accepts responsibility for whatever the disability will mean to that child and to her and the rest of her family. In that case, her child, her family, and the rest of society can reproach her for having so-to-speak “caused” that human being’s physical pain as well as the social pain he or she experiences because our society does not look kindly on people with disabilities.

There is something terribly wrong with this situation, and although it differs in many ways from what went wrong in Germany, at base are similar principles of selection and eradication. Lest this analogy seem too abstract, let me give a few examples of how the principle of selection and eradication now works in practice.

Think of people who have Huntington’s disease; as you may remember they were on the list of people to be sterilized in Germany. Huntington’s disease is a degenerative disease of the nervous system and is unusual among hereditary diseases in that it is inherited as what geneticists call a dominant trait. In other words, even people in whom only one of the pair of genes that is involved with regulating the relevant metabolic processes is affected manifest the disease. Most other gene-mediated diseases, such as Tay-Sachs disease or sickle-cell anemia, are so-called recessives: Only people in whom both members of the relevant pair of genes are affected manifest the disease. In the case of recessive diseases,

people with only one affected gene are called carriers: They do not have the disease and usually do not even know that they carry a gene for it. To inherit a recessive disease such as sickle-cell anemia, a child must get an affected gene from each of its parents; to inherit a dominant disease, such as Huntington's disease, it is enough if she or he gets an affected gene from either parent.

The symptoms of Huntington's disease usually do not appear until people are in their thirties, forties, or fifties—in other words, after most people who want to have children have already had one or more. Woody Guthrie had Huntington's disease, but he did not become ill until after he had lived a varied and productive life, produced a large legacy of songs, and fathered his children. At present, there is no cure for Huntington's disease, although scientists have been working to find one. However, a test has been developed that makes it possible to establish with fair reliability whether a person or fetus carries the gene for Huntington's disease, provided a sufficient number of people in that family is willing to be tested.

The existence of this test puts people with a family history of Huntington's disease in an outrageous position: Although they themselves are healthy and do not know whether they will get the disease, they must decide whether to be tested, whether to persuade as many of their relatives as possible to do the same, and whether to test their future child prenatally so they can terminate the pregnancy if the test reveals that the fetus has the gene for Huntington's disease. If it does and they decide on abortion, they are as much as saying that a life lived in the knowledge that one will eventually die of Huntington's disease is not worth living. What does that say about their own life and the lives of their family members who now know that they have the gene for Huntington's disease? If the fetus has the gene and they do not abort, they are knowingly wishing a cruel, degenerative disease on their future child. And if they refuse the test, they can be accused of sticking their heads in the sand. This is an obscene "choice" for anyone to have to make!

Some other inherited diseases also do not become evident until later in life, such as retinitis pigmentosa, a degenerative eye disease. People with this disease are born with normal vision, but their eyesight deteriorates, although usually not until midlife, and they may eventually lose their sight. (People with this disease presumably also were slated for sterilization by the Nazis because it is a form of "hereditary blindness.") There are different patterns of inheritance of retinitis pigmentosa, and prenatal diagnosis is becoming available for one of these patterns and being sought for others. What are prospective parents to do when confronted with the "choice" of aborting a pregnancy because their future child may become blind at some time during its life?

Another, rather different, problem arises with regard to the so-called neural-tube defects (NTDs), a group of developmental disorders which, in fact, are not inherited. They include anencephaly (failure to develop a brain) and spina bifida (failure of the spinal column, and sometimes also the overlying tissues, to close properly). Babies with anencephaly die before birth or shortly thereafter. The severity of the health problems of children who have spina bifida depends on where along the spinal column the defect is located and can vary from life-threatening to relatively mild. The incidence of NTDs varies geographically and tends to be higher in industrialized than in nonindustrialized areas. Women who carry a fetus with a neural-tube defect have a greater than usual concentration of a specific substance, called alpha-feto-protein, in their blood. A blood test has been developed to detect NTDs prenatally, and California now requires that all pregnant women in the state be offered this test. The women are first counseled about NTDs and about the test and then have to sign a consent or refusal form. If they refuse, that is the end of it. If they consent, they can later refuse to abort the fetus even if the test is positive. This procedure sounds relatively unproblematic, although the requirement to sign a refusal form is coercive. (You cannot walk away; you must say no.) The trouble is that although the test detects virtually all fetuses who have NTDs, it yields a large number of false positive results that suggest that the fetus has a NTD although it does not.

Let us look at some numbers. In California there are about two hundred thousand births a year

and the incidence of NTDs is about one per thousand. So, about 200 pregnant women a year carry fetuses with NTDs and 199,800 do not. However, about 5 percent of women test positive on a first test. In other words, if all pregnant women agreed to be tested, 10,000 women would have a positive test, 9,800 of which would be false positives. Those 10,000 women would then have to undergo the stress of worrying as well as further tests in order to determine who among them is in fact carrying a fetus with a NTD. And no test will tell the 200 women whose fetus, in fact, has a NTD how severe their child's health problem will be. All this testing with uncertain results must be offered at this time, when health dollars in California, as elsewhere, have been cut to the bone, and increasing numbers of pregnant women are coming to term with little or no prenatal services of any sort.

The reason I have spelled this problem out in such detail is to make it clear that in many of these situations parents have only the most tenuous basis for making their decisions. Because of the fear of raising a child with a serious disability, many women "choose" to abort a wanted pregnancy if they are told that there is any likelihood whatever that their future child may have a health problem. At times like that we seem to forget that we live in a society in which every day people of all ages are disabled by accidents—at work, on the street, or at home—many of which could be prevented if the necessary money were spent, the necessary precautions taken. What is more, because of the deteriorating economic conditions of poor people and especially women, increasing numbers of babies are born with disabilities that could easily be prevented and are prevented in most other industrialized nations. I question our excessive preoccupation with inherited diseases while callousness and economic mismanagement disable and kill increasing numbers of children and adults.

To say again, I am not arguing against a woman's right to abortion. Women must have that right because it involves a decision about our bodies and about the way we will spend the rest of our lives. But for scientists to argue that they are developing these tests out of concern for the "quality of life" of future children is like the arguments about "lives not worth living." No one can make that kind of decision about someone else. No one these days openly suggests that certain kinds of people be killed; they just should not be born. Yet that involves a process of selection and a decision about what kinds of people should and should not inhabit the world.

German women, who know the history of Nazi eugenics and how genetic counseling centers functioned during the Nazi period, have organized against the new genetic and reproductive technologies (Duelli Klein, Corea, and Hubbard, 1985). They are suspicious of prenatal testing and counseling centers because some of the scientists and physicians working in them are the same people who designed and implemented the eugenics program during the Nazi period. Others are former co-workers or students of these Nazi professors.

Our history is different, but not different enough. Eugenic thinking is part of our heritage and so are eugenic sterilizations. Here they were not carried over to mass exterminations because we live in a democracy with constitutional safeguards. But, as I mentioned before, even in recent times black, Hispanic, and Native-American women have been sterilized against their wills (Rodriguez-Trias, 1982). We do not exalt the body of the people, as a collective, over that of individuals, but we come dangerously close to doing so when we question the "right" of parents to bear a child who has a disability or when we draw unfavorable comparisons between the costs of care for children with disabilities and the costs of prenatal diagnosis and abortion. We come mighty close when we once again let scientists and physicians make judgments about who should and who should not inhabit the world and applaud them when they develop the technologies that let us implement such judgments. Is it in our interest to have to decide not just whether we want to bear a child but what kind of children to bear? If we try to do that we become entirely dependent on the decisions scientists and physicians make about what technologies to develop and what disabilities to "target." Those decisions are usually made on grounds of professional interest, technical feasibility, and economic and eugenic considerations, not out of a regard for the needs of women and children.

## Problems with Selective Abortion

I want to be explicit about how I think a woman's right to abortion fits into this analysis and about some of the connections I see between what the Nazis did and what is happening now. I repeat: A woman must have the right to abort a fetus, whatever her reasons, precisely because it is a decision about her body and about how she will live her life. But decisions about what kind of baby to bear inevitably are bedeviled by overt and unspoken judgments about which lives are "worth living."

Nazi eugenic practices were fairly coercive. The state decided who should not inhabit the world, and lawyers, physicians, and scientists provided the justifications and means to implement these decisions. In today's liberal democracies the situation is different. Eugenic principles are part of our largely unexamined and unspoken preconceptions about who should and who should not inhabit the world, and scientists and physicians provide the ways to put them into practice. Women are expected to implement the society's eugenic prejudices by "choosing" to have the appropriate tests and "electing" not to initiate or to terminate pregnancies if it looks as though the outcome will offend. And to a considerable extent not initiating or terminating these pregnancies may indeed be what women want to do. But one reason we want to is that society promises much grief to parents of children it deems unfit to inhabit the world. People with disabilities, like the rest of us, need opportunities to act in the world, and sometimes that means that they need special provisions and consideration.

So once more, yes, a woman must have the right to terminate a pregnancy, whatever her reasons, but she must also feel empowered not to terminate it, confident that the society will do what it can to enable here and her child to live fulfilling lives. To the extent that prenatal interventions implement social prejudices against people with disabilities they do not expand our reproductive rights. They constrict them.

Focusing the discussion on individualistic questions, such as every woman's right to bear healthy children (which in some people's minds quickly translates into her duty not to "burden society" with unhealthy ones) or the responsibility of scientists and physicians to develop techniques to make that possible, obscures crucial questions such as: How many women have economic access to these kinds of choices? How many have the educational and cultural background to evaluate the information they can get from physicians critically enough to make an informed choice? It also obscures questions about a humane society's responsibilities to satisfy the requirements of people with special needs and to offer them the opportunity to participate as full-fledged members in the culture.

Our present situation connects with the Nazi past in that once again scientists and physicians are making the decisions about what lives to "target" as not worth living by deciding which tests to develop. Yet if people are to have real choices, the decisions that determine the context within which we must choose must not be made in our absence—by professionals, research review panels, or funding organizations. And the situation is not improved by inserting a new group of professionals—bioethicists—between the technical professionals and the public. This public—the women and men who must live in the world that the scientific/medical/industrial complex constructs—must be able to take part in the process by which such decisions are made. Until mechanisms exist that give people a decisive voice in setting the relevant scientific and technical agendas and until scientists and physicians are made accountable to the people whose lives they change, technical innovations do not constitute new choices. They merely replace previous social constraints with new ones.

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