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Constructions of Deafness

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ABSTRACT *As a social problem, deafness can be variously construed. Each of the primary constructions of deafness today—disability and linguistic minority—has its archetypes but most deaf children match neither of them. Organizations espousing each construction compete to ‘own’ deaf children and define their needs. As with service providers for blind people, the troubled-persons industry associated with deafness seeks conformity of the client to the underlying construction of deafness as disability. Some spokespersons in the disability rights movement have joined service providers in promoting the disability construction of all deafness. This neglects the fact that the DEAF-WORLD has a distinct culture and that deafness is constructed differently in that culture than it is in national cultures of hearing peoples. The implications of a shift toward the linguistic minority construction for deaf children and adults, the obstacles to such change, and the forces promoting change are examined.*

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 50 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 are 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 from 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 US, National organizations primarily associated with deafness as disability include the A. G. Bell Association (4500 members), the American Speech-Language Hearing Association (40,000), the American Association of Late-Deafened Adults (1300) Self Help for the Hard of Hearing (13,000), the American Academy of Otolaryngology, Head and Neck Surgery (5600), and the National Hearing Aid Society (4000). 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 (2700), and 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 anyone 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 US 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 legitimate 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 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 lighthouse 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 make 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

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 a 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). US 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 US 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% 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 daughter 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 US 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 this 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 [1]. 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 UN *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, nor place any special value on rehabilitation or personal assistance services [2], nor 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% of the time in the US (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% of the noninstitutionalized population of the US 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 construc-

tion 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 [3]. 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 US 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 US (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 US 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 US 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 Communication 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 US) 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 Deaf 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% 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 US National Institute on Deafness and Other Communication 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 bind—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 bind, 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, this past year has 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).

Producing 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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