

Exploring theories and expanding methodologies: where we are and where we need to go

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5. EXAMINING THE FIT BETWEEN DEAFNESS AND DISABILITY

Susan Foster

INTRODUCTION

At the author's university, job announcements are posted through electronic mail. The following statement is routinely included: "Ability to contribute in meaningful ways to the college's continuing commitment to cultural diversity, pluralism, and individual differences strongly preferred. *People who are deaf or hard of hearing, with a disability, are women and/or members of a minority group are encouraged to apply*" (italics added). This statement captures the current debate in the field of deafness – is deafness a disability or is it a condition of linguistic minority status?

At a time when the disability community is defining itself as having a culture and calling for a celebration of differences rather than exclusive focus on conformity and inclusion, why is it that people who consider themselves culturally Deaf¹ often distance themselves from the disability movement? If deafness is not a disability, should deaf persons be entitled to SSI payments, special schools, and the protection of laws such as the Americans with Disabilities Act? What are the implications of a linguistic minority definition of deafness for educational policy and practice? In this chapter, these and other questions are tied to an examination of the "fit" between deafness and disability, and the place of deafness in the growing field of disability studies.

The chapter is divided into three sections. In the first section, three models of disability are reviewed, and the impact of these models on the field of deafness is discussed. In the second section, areas of similarity and difference

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between deafness and disability are examined. The chapter is concluded with a discussion of the “fit” between deafness and disability, and the implications of this to fit for disability studies and deaf studies.

SECTION ONE: THREE MODELS OF DISABILITY, AND THE IMPLICATIONS OF EACH FOR DEAFNESS²

The condition of “disability” has been defined in several ways. In each instance, the model used has had far reaching implications for the ways in which disabled people, including deaf people, are viewed and treated. In this section, three major models of disability are described; they are (1) medical, (2) social construction, and (3) political.

Medical Model: Disability as an Individual Problem

Generally, the medical model assumes that whatever problems the disabled individual is experiencing can be traced to that person, and defined in terms of some form of physical or mental abnormality; in other words, the problems associated with the condition reside *within* the individual. As a result, diagnosis and treatment revolve around the disabled person and involve tests, evaluations, and interventions that are applied to the individual. Such a model also places responsibility for rehabilitation with the disabled person, in that he or she must define him or herself as impaired and willingly participate in the process of diagnosis and treatment. Inherent in the medical model is a belief in the expert and active role of specialists, with corresponding weight and credibility attached to expert opinion. Terms used in the medical model include “diagnosis”, “prescription”, “affliction”, “defect”, “stages of acceptance”, “rehabilitation”, “prevention”, and “cure”.

The medical model has traditionally been the most widely held model of deafness. Also referred to as a clinical infirmity, or pathological model, the medical model of deafness is grounded in the belief that the condition represents *failure* of a critical sensory system and is, therefore, impairment. Implicit in this interpretation is the belief that something is broken, e.g. the ear; remediation necessarily involves repair of, or compensation for, the defect. The goal of remediation is generally restoration of the deaf individual, both physically and socially, to the mainstream of society by reducing the differences and enhancing sameness, or conformity.

Within a medical model, deafness is a defect to be avoided, and the focus of remediation is almost always on the deaf individual. It is the individual who is

affected, who must be treated (and submit to treatment), who will hopefully be rehabilitated and restored. Whether the treatment is medical (surgery, medicines), technical (hearing aids, cochlear implants), educational (special curricula, individualized education plans), vocational (rehabilitation), or psychological (therapy), the focus is on the deaf person and on oral speech versus American Sign Language (ASL). Diagnosis, prognosis, and treatment are managed by specialists trained in the various professions described above (physicians, audiologists, teachers of “the deaf”, speech-language pathologists, counselors). The language employed within a medical model reflects these patterns; i.e. “hearing loss”, “hearing impaired”, “speech therapy”, “communication disorders”.

The medical model has had an impact on scholarship and research in deafness. The tremendous growth of the field of audiology after World War II, and the strong links between audiology and medicine, served to strengthen the relationship between medicine and deafness. Many of the causes of deafness have been linked to illness or heredity; for example, the rubella epidemic of 1963–65 resulted in the birth of approximately 8000 infants with some degree of hearing loss (Stuckless & Walter, 1983). Research in audiology and speech-language pathology has played a major role in the field, including studies that are physiological as well as psychological in nature. Much of this work has focused on the function of the auditory or speech systems, the development of medical or mechanical technologies and therapies designed to restore a measure of hearing or enhance the ability to speechread or speak, or the individual’s ability to accept and/or adapt to their deafness (Bender, 1981; Liben, 1978; Myklebust, 1964). More recently, specialists working within the medical model of deafness have pursued advancements in the fields of genetic research (linking genes to deafness), miniaturization of hearing aids, and the development of cochlear implants.

Social Construction Model: Disability as a Social Construct

Beginning in the 1960s and continuing through the present, the medical model of disability has been challenged through the works of Thomas Szasz, (1961), Howard Becker (1963), Erving Goffman (1961, 1963), Dorothea and Benjamin Braginsky (1971), Jane Mercèr (1973), Robert Bogdan and Steven Taylor (1976), Frank Bowe (1978, 1980), and Mike Oliver (1983, 1986), among others. These scholars propose that the experience of people with disabilities can best be understood as a function of interaction between the individual and society, and that the meaning of such concepts as impairment, handicap and disability³ is socially constructed. Within this model, also referred to in the

literature as interpretive, or interactionist, interventions focus on the environment as well as the individual, and the perspectives of persons with disabilities assume positions of authority in defining the experience of being disabled.

The social construction model calls for a critical examination of the design, method and interpretation of disability research. Studies conducted within this model include examination of the environment in descriptions and explanations of the experiences of the individual. The judgment and behavior of professionals and other experts is subjected to the same scrutiny as was reserved in the past only for the disabled person (Scott, 1969; Conrad & Schneider, 1980). Popular culture is analyzed in order to better understand the sources of prejudice and stereotypical images of disabled people (Zola, 1987, 1985; Bogdan et al., 1982; Kriegel, 1982). Social attitudes are a focus of study and discussion (Makas, 1988).

Within the social construction model, concepts such as "hearing impairment", "deaf and dumb", and "rehabilitation", are understood as the reflections of social understandings of what it means to be deaf, as well as the perspectives of those who use these terms. Barriers experienced by deaf people in daily life activities, such as shopping, going to school, or attending public gatherings, are considered a function of linguistic and cultural differences between the majority (hearing) and minority (deaf) group. "Bilingual", Deaf culture", and "linguistic minority" are examples of terms used by those who adhere to a social construction model of deafness.

Applications of this model to research and scholarship in the field of deafness are reflected in rich descriptions of the history, language, and culture of deaf people (Sacks, 1989; Van Cleve & Crouch, 1989; Padden & Humphries, 1988; Groce, 1985; Lane, 1984; Stokoe, 1960), as well as studies of the ways in which deaf people have been portrayed in popular culture (Hafferty & Foster, 1994; Gershon, 1992; Schuchman, 1988). Work has also been done that focuses on understanding the experience of deaf people from their perspectives and in their words. For example, Foster (1989c), Seidel (1982), Becker, (1980), and Higgins (1980) have examined the community and culture of deaf people. Other studies have described the experiences of deaf persons in employment (Emerton et al., 1987; Foster, 1987, 1992; Crammatte, 1968) and education (Foster, 1988, 1989a, b; Mertens, 1989; Saur et al., 1986).

Political Model: Disability as an Advocacy and Policy Issue

Within the last ten years, criticisms have been raised with regard to both the medical and social construction models. The basis for these criticisms is that both these models are shaped by traditional power relationships between

disabled and non-disabled people, with consequent alienation and oppression of disabled people (Hahn, 1985, 1988; Oliver, 1992; Scotch, 1984; Zarb, 1992). The political model, also referred to as emancipatory, reframes the concept of disability in terms of power – i.e. power to define disability, to determine what treatments (if any) should be applied, and the power to claim equal status and rights within the larger society. Within this model, the perspectives of people with disabilities assume greater authority than those of non-disabled experts in the development of agendas for action, study, and policy. Language typically used within the political model includes “emancipation”, “civil rights”, “control”, “power”, “empowerment”, and “oppression”. While culture is an important element of the political model, it is more often framed in terms of relative power and distribution of resources rather than social acceptance or inclusion.

Within the political model, deafness is viewed as a condition of a linguistic minority that has suffered oppression at the hands of the hearing majority. Historically, it is argued, deaf people have had less power than hearing people, so the latter have been able to impose definitions of deafness on deaf people, including definitions of deafness as a disability. Hearing people have also controlled access to resources and have been the guiding force in treatment and policy decisions which affect the lives of deaf people. The political model of deafness suggests that hearing persons can never fully understand the experiences of deaf people, any more than men can fully understand women’s perspectives or caucasians can understand the perspectives of blacks. As a result, no matter how well intentioned, hearing people should not be in positions of control over the destinies or treatment of deaf persons.

The focus in a political model of deafness often revolves around civil rights, public policy, and control of resources. For example, the Deaf President Now (DPN) movement at Gallaudet University has often been cited as an instance in which deaf students and their mentors fought for and won the right to a deaf leader for Gallaudet (Christiansen & Barnartt, 1995). Similarly, the Americans with Disabilities Act of 1990 (ADA), which guarantees deaf people certain rights regarding communication access and accommodations, was viewed as a “civil rights law” for people with disabilities.

Studies in deafness have been carried out within a political framework. For example, Baker-Shenk and Kyle (1990) examine conflict between hearing scholars and the deaf community in the field of linguistic studies. They conclude that hearing researchers should become aware of areas in which conflict is likely to arise and make adjustments that empower rather than alienate deaf people. Other researchers have examined the history of deaf

people in terms of power and oppression (Lane, 1992) and the role of political activism within the deaf community (Bateman, 1991).

Making Sense of the Models

What should we make of these various, and often competing, models of disability and deafness? One possible interpretation of the models is that they are evolutionary, e.g. the medical model has been superseded by the social construction model, which in turn is now being replaced by the political model. Inherent in this interpretation is the belief that subsequent models represent an improvement over the model they have replaced.

A second interpretation is that the medical model is the only “real” or enduring model. Within this interpretation, the social construction and political models are discredited as fads, which are more indicative of the social and political climate of the 1960s–1990s. A related notion is that the social construction and political models are promoted by a small core of radicals within disability and deaf communities, and as such cannot be taken seriously or viewed as representative of these communities.

Neither of these interpretations is helpful, nor do they adequately reflect the social and political realities in America today. Major government funding for such programs as the Human Genome Project and the Disability Prevention Program, each of which includes elements related to deafness, indicates that the medical model of disability and deafness remains very powerful. Many deaf people and people with disabilities desire or require medical interventions designed to prevent, improve, or cure their deafness or disability. For these people, medical research, access to rehabilitation services, and the advice of experts are valued resources. On the other hand, there can also be little doubt that the social construction and political models have sparked major trends in this country with regard to persons who are disabled and/or deaf. Mainstream education for students with disabilities, the Americans with Disabilities Act, the Deaf President Now movement, and positive portrayals of deaf and disabled persons in the media are but a few examples of ways in which these models have changed the American landscape with regard to persons with disabilities.

Rather than attempting to identify which model is the most accurate, representative, or useful, it may be more fruitful to think of them as different perspectives on disabilities and deafness. Each may have a useful application under certain conditions, or within certain limits. It is doubtful that any of the models can adequately address all aspects of the experiences of persons who are deaf and/or disabled. It is also probably healthy that there are competing

models, since each model encourages proponents of the other models to review and question their assumptions and approaches to disabilities and deafness.

Connecting the Models to Disability Studies

Definitions of “disability studies” suggest that the field is closely connected to the social construction and political models of disability, but not to the medical model. For example, Pfeiffer and Yoshida (1995) make clear the difference between the medical paradigm and the disability studies paradigm when they write, “In the medical model disability is a health question. In the disability studies paradigm disability is a policy and political question” (p. 478). Other scholars have explored the role of disability studies in expanding college curricula and the social construction of knowledge:

Disability studies challenges the idea that the social and economic status and assigned roles of people with disabilities are inevitable outcomes of their condition, an idea similar to the argument that women’s roles and status are biologically determined. But disability studies goes beyond cataloguing discrimination and arguing for social change. It challenges the adequacy of the content and structure of the current curriculum. As with women’s studies, disability studies redresses omitted histories, ideas, or bodies of literature and also analyzed the construction of the category “disability”, the impact of that construction on society, and on the content and structure of knowledge – fundamental epistemological issues (Linton, Mello & O’Neill, 1995, p. 5).

Deafness has clearly been defined from the medical, social construction and political perspectives, as has disability. To the degree that it has social construction and political dimensions, it may fit within the broad disability studies paradigm. Yet many within the Deaf culture would argue against such a fit. On what grounds? And with what implications? These questions guide the remaining sections of this chapter.

SECTION TWO: SIMILARITIES AND CONTRASTS BETWEEN DEAFNESS AND DISABILITY

This chapter began with an examination of some of the major models that have been used historically as well as currently to define disability and deafness in America. In this section we examine the similarities and contrasts between deafness and disability. On what points do they converge? On what points do they differ? The section is divided into two parts. In the first part, areas of agreement, or convergence between deafness and disability, are described. In the second part, those areas in which deafness and disability perspectives differ from one another are examined.

Points of Convergence Between Deafness and Disability

There are many points of agreement, or convergence, between deafness and disability. At the most general level, deafness and disability *share a history of definition and experience* within each of the three models described in the first part of this chapter. For both disability and deafness, the medical model has been (and remains) a powerful defining paradigm. More recently, members of both the deaf and disabled communities have begun to identify themselves as members of minority groups, and draw parallels between their status and that of other historically oppressed groups, such as women and black persons:

Equally important is the influence of other rights movements. People with disabilities, especially those on college campuses, were often involved in anti-Vietnam era protests. Some were involved in Black civil rights causes, and many of the women were influenced by the feminist movement of the 1970s. Disability rights leaders speak of their realization that the rights embedded in these other movements could and should be expanded to their rights as persons with disabilities (Brannon, 1995, p. 4).

Just as women and African Americans have defined themselves as having a special culture, history and political agenda, so have deaf and disabled persons. Many deaf and disabled people have extended these connections to frame political activism such as that reflected in the ADA of 1990 or the DPN movement in terms of a new civil rights movement.

Disability and deafness scholars have developed similar vocabularies and metaphors to describe the minority identity of the group. One example is the use of the uppercase “D” in reference to Disability culture and Disabled persons (e.g. Gill, 1995) as well as Deaf culture and Deaf persons (e.g. Padden & Humphries, 1988). Generally, this notation is used to emphasize the minority group and cultural status of the persons so described. In descriptions of deaf persons, it is also used to distinguish within the group between those who consider themselves to be part of a minority culture and those who do not (Padden & Humphries, 1988; Bienvenu, 1991).

A second example is the application of the “colonization” metaphor, and its corollary “paternalism”, to the experiences of deaf persons and persons with disabilities. For example, Hirsch and Hirsch (1995) apply this metaphor to persons with disabilities:

Colonization is a phenomenon that is rooted in the modern world view – colonized people need to be conquered and educated by the colonizers to become part of the modern world If people with disabilities are the “colonized” people, and the “helping professionals” are the colonizers, the struggle of the oppressed to free themselves takes place within institutions that the colonizers established: residential institutions, group homes, nursing homes, special education, and vocational rehabilitation While

individuals with disabilities are still seen as generally incapable of exercising self government and wielding sovereign authority over wealth and power in the modern world, the medical model and its paternalistic implications that were imposed upon people with disabilities by the helping professions, are being rejected and replaced by a minority group model People with disabilities are using legal and political means to gain control over service delivery programs, educational institutions, and public policy developments. The “natives” are rebelling against the colonizers and taking power and control away from them (Hirsch & Hirsch, 1995, pp. 22–23).

Similarly, Lane (1992) describes parallels between Africa’s paternalistic colonial history and the oppression of deaf communities:

Paternalism, whether that of the colonizers in Africa or that of hearing professions concerned with deaf communities, is benighted, unsuccessful, and selfish, but the catalog of its evils does not end there. Paternalism places its beneficiaries in a dependent relation and keeps them dependent for its own psychological and economic interest. Paternalism deprives its beneficiaries of their history and therefore of the possible lives they can envision. Paternalism corrupts some members of the oppressed minority, forming a class who conspire with the authority to maintain the status quo. Paternalism evades responsibility for its failure by affirming the biological inferiority of the beneficiary. Allowed to endure, paternalism instills the benefactor’s values in the beneficiary – the oppression is internalized. And in the end, the beneficiaries despise the benefactors who have so long despised them, and the benefactors decry the thanklessness of their jobs (Lane, 1992, pp. 38–39).

Yet a third example has evolved from the terms “racism” and “sexism”. Bogdan and Biklen (1977) coined the term “handicappism” to describe “a set of assumptions and practices that promote the differential and unequal treatment of people because of apparent or assumed physical, mental, or behavioral differences” (p. 14). Similarly, Lane (1992) defined the term “audism” as “the hearing way of dominating, restructuring, and exercising authority over the deaf community” (p. 43).

The case has been made for both disability and deafness that they are *handicaps only under certain social conditions*. For example, it is not a handicap to use a wheelchair when there are curb cuts, accessible bathrooms, phones placed at appropriate heights, and elevators. When written materials are provided in Braille, blind persons are not at a disadvantage. Similarly, it has been argued that deafness is not a handicap at the local deaf club or when interpreters are available, because the language differences disappear. Indeed, Groce’s (1985) study of deafness on Martha’s Vineyard recorded a place and time where deafness was not handicapping because all the islanders (both deaf and hearing) knew sign language.

Both deaf and disabled people experience *barriers to learning about their culture(s)*, and generally enter the culture as young adults or adults. One reason for this is that persons with disabilities and deaf persons are generally born to non-disabled or hearing parents. Another has to do with demographics – for many, opportunities to meet and interact with other disabled or deaf persons are restricted. In these cases, a visible Deaf or Disability culture serves as a beacon to deaf or disabled persons (Padden & Humphries, 1988; Gill, 1995).

A major source of controversy in both disability and deafness involves the *role of non-disabled or hearing people* in research, leadership, and political activism. In particular, the political model of disability and deafness has frequently called for restrictions on the roles or influence of non-disabled or hearing people in these activities. For example, in his discussion of an “emancipatory research paradigm”, Oliver (1992) suggests that researchers “learn how to put their knowledge and skills at the disposal of their research subjects, for them to use in whatever ways they choose” (p. 111). In discussing the question of research on deaf individuals by hearing persons, Stinson (1993) writes that “as a deaf researcher, I seem to have a weighing system where if something is written by a person who is deaf, it receives extra weight because of the commonality of the deaf experience, even if I disagree with the particular writer’s perspective” (p. 19). Bienvenu (1991) proposes that “non-Deaf” people have no right to define what it means to be Deaf: “It’s about time we Deaf people declare who we are without having our community defined and described by non-Deaf professionals who more than likely have not taken one course in ASL or American Deaf Culture” (p. 21).

More often, a middle ground has been proposed. For example, a collaborative strategy proposed by Foster (1993) involves the formation of partnerships between deaf and hearing researchers. Woodill suggests that some able-bodied persons can participate in the disability rights movement under certain conditions, e.g. that “they do not assume a leadership position in the movement, they enjoy the support of an organization of disabled people which has asked them for their participation, and they are prepared to learn to see the world from the perspective of a person with a disability” (p. 47). Altman (1994) and Batavia (1994) recommend a separation of roles in their discussions of who can be researchers and advocates. Watson and O’Day (1996) and Foster (1993) describe the potential “downside” of requiring particular physical characteristics in order to be associated with a disability or deaf research project/political movement, e.g. that deaf or disabled persons might find themselves equally restricted in their choices (limited to disability or deaf areas and causes, or evaluated on the basis of their physical characteristics rather than their experience and skills).

Points of Difference Between Deafness and Disability

In some important ways, deafness has also been defined, experienced, and described as different than disability. One major distinction involves the proposition that *culturally Deaf persons constitute a linguistic minority rather than a disability group* (Lane, 1995a; Bienvenu, 1991). Many arguments have been made in support of this perspective, but the most powerful is probably that culturally Deaf persons generally choose to communicate using ASL,⁴ and as such they form a language community that has more in common with other linguistic minority groups than with disability communities.

A second, and related, difference between the deaf community and the disability community is *interpretation of PL94-142* and the ensuing trend towards mainstreaming all children with disabilities in public schools (Lane, 1984; Van Cleve & Crouch, 1989; Higgins, 1990; Foster & Emerton, 1991). While the disability rights movement has focused on inclusion in schools and viewed mainstreaming as a major breakthrough, culturally Deaf persons have interpreted integration as a form of cultural genocide. The reason is that special or separate schools for deaf students, generally referred to as “schools for the deaf”, have been the incubators for and transmitters of Deaf culture. Without them, it is argued, deaf children may have few or no opportunities to meet the deaf peers and deaf adults who will help them to learn ASL and become part of the Deaf culture. As mainstreaming has become the predominant model for educating all children with disabilities, many of the schools for the deaf have lost enrollments, and some have closed, a trend which led Roe and Roe (1993) to describe PL94-142 as “a popular law . . . that has been a boon for children with physical handicaps but a bane for children with deafness” (p. 146).

A more subtle distinction between deafness and disability is that, in the latter, there has been a greater correlation drawn between *cultural consciousness and political action*. For example, Brannon (1995) notes that “part of the agenda-building process of the disability rights movement has been an appeal to cultural concepts to foster group identity, to build coalitions among differing disability groups, and to aid the search for empowerment” (p. 3). Similarly, Gill (1995) describes four functions of Disability culture, each of which is linked to the development of a political as well as social identity; they are, (1) fortification, (2) unification, (3) communication, and (4) recruitment. Deaf culture and deaf communities, on the other hand, long pre-existed the deaf rights movement, most probably because the primary bond was shared language rather than oppression or civil rights. Many deaf organizations, especially local groups such as community deaf clubs, have as a primary focus the creation of opportunities for social interaction and fellowship rather than

political action,⁵ and deaf leaders have expressed frustration in efforts to mobilize the deaf community for political activity (Batemen, 1991). Deaf persons are far more likely to gather for purely social purposes than are persons with disabilities, and approximately 86% of deaf married persons are married to another deaf or hard of hearing person⁶ (Schein & Delk, 1974).

A review of *major topics covered in disability studies and deaf studies curricula* illustrate the relative importance of advocacy and politics within each field. In their analysis of disability studies courses in the 1980s and 1990s, Pfeiffer and Yoshida (1995) found five topics that were covered in 50% or more of the courses; these are, (1) attitudes, (2) advocacy, (3) definitions, (4) developmental disabilities, and (5) politics. A review of deaf studies programs at Gallaudet University and NTID suggests a different focus. At Gallaudet, the introductory deaf studies course is designed to help students “develop a special focus on the sociological, historical, linguistic, and psychological aspects of people with different degrees of hearing loss” (Gallaudet University Course Book, p. 50). Elective courses within the deaf studies program cover three thematic areas – culture, community, and language. Examples of courses offered include “Comparative Poetics: ASL and English” (Culture), “History of Mass Media and the Deaf Community” (Community), and “Bilingual Aspects in Sign Communication” (Language). Deaf studies at NTID is intended to “give students the opportunity to develop a strong knowledge base which includes the American Sign Language, historical, anthropological, linguistic, literary, artistic, and multicultural aspects of Deaf culture and the deaf community” (Preliminary Rationale . . . , p. 1). Those students who select a concentration in ASL or Deaf Studies will complete coursework in five areas: American Sign Language, Sign Language Teaching, Creative Arts and Literature, Advocacy and Community, and Deaf History. While advocacy is a core topic in the NTID curriculum (and there are also several elective course options related to policy and human rights in the Gallaudet curriculum) the emphasis in these programs is clearly on language, history, and art, rather than on politics.

A metaphor for understanding the difference between disability and deafness can be found in the terms that members of these communities have identified as *preferred “ways of naming”*. For example, the generally accepted term for members of the first group is “people with disabilities”, in which the primary emphasis is on people, and the identity of disability placed second. The phrase “people who are deaf”, however, is generally not the preferred choice by members of the deaf community. A deaf colleague offered the following explanation for this preference:

There has been a movement in the disabled community to do away with labels and for this reason the handicapping condition of a person should be de-emphasized. Thus people who are deaf would be preferable over deaf people. However, many people in the deaf community do not agree. (It appears that deaf people are often at odds with other groups in the disabled community over various issues.) Anyhow, many deaf people do not feel the need to cover their identity as a deaf person. This phrase . . . "people who are deaf" seems to be as ridiculous as . . . "people who are black" or "people who are women" or . . . "people who are gay . . ." The preferred terms for these groups would be black people (or African-Americans), women, gay people and so on. I have also noticed among many deaf people (including myself) that we would get upset if there was no reference to a person being deaf if there was a story about him/her in the newspaper. An identity as a deaf person is so important to many of us that we feel offended when the word "deaf" is omitted when we make the news. Again, I know many people in the disabled community find it unnecessary and offensive when the disability is specified in the story, especially when the story has nothing to do with the disability itself (Thomas Holcomb,⁷ personal communication, 3/31/96).

So it is with many deaf persons, and in particular with people who consider themselves to be culturally Deaf. Deaf community, deaf children, deaf adults, Deaf President Now(DPN) – in each of these phrases, the term "deaf" is placed first. This sense of pride and the primary role assigned to being deaf is also at the core of the linguistic minority concept as it is applied to deaf people and the corresponding call for separate education through which the Deaf identity and culture can be developed and preserved.

Another difference between the deaf and disability communities is the *importance of "place"* for many deaf people (Lane, 1995b; Van Cleve & Crouch, 1989). "That Deaf Americans should feel they have a place of their own, that such a conception is needed to organize the prominent facts of American Deaf history, testifies to quite a different construction of deafness than the one based on disability spelled out earlier" (Lane, 1995b, p. 76). Residential schools for the deaf are only one example of "shared place". Deaf clubs, "tiny reservations of deafness across America, where Deaf people govern, socialize and communicate fluently in ASL when the work day . . . is over", is another (Lane, 1995b, p. 76). Gallaudet University has also become a special place for deaf people, as the only Deaf university in America. Admissions research conducted with students at the National Technical Institute for the Deaf (NTID), a college of Rochester Institute of Technology serving approximately 1100 deaf students, documents the need of many deaf young adults for opportunities to participate in a community of deaf persons (Foster & Elliot, 1987). As noted by both Lane (1995b) and Van Cleve and Crouch (1989), deaf people have even sought from time to time to establish a deaf state, a kind of utopian vision of a land populated and controlled exclusively by deaf citizens.

An obvious but perhaps underestimated difference between deafness and disability is that *most people with disabilities are not deaf*. This difference maintains a sense of distance between disabled and deaf persons much like that between deaf persons and other hearing persons. As a friend pointed out, "many deaf people still feel disabled or handicapped in the disabled community. For example, the isolating experience would be as severe for a deaf person in a room full of disabled individuals as it would be in a place where there is no other disabled person. For this reason, there is no distinction between disabled people and hearing people for us. They are still "hearing"! It's like when women claim that it is a men's world or black people say it's a white world with no special categories for other minority groups. We see the world as the hearing world, including those who are disabled. (Thomas Holcomb, personal correspondence).

A core distinction between deafness and disability is that, at least *among culturally Deaf people, deafness is not considered a disability*. In this regard, culturally Deaf people may welcome the birth of a deaf child. As Lane (1995a) notes, "American Deaf people . . . 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" (p. 178). Moreover, most culturally Deaf persons would not choose to receive treatments, such as cochlear implants, which would make them hearing, even if these treatments were guaranteed to be 100% successful (D'Antonio, 1993).

The result of these differences between deafness and disability is that the two have often had what Padden and Humphries (1988) call an "uneasy" alliance. Almost always, the reasons for the alliance are political or economic. For example, deaf and disabled people worked together to ensure passage of the Americans with Disabilities Act of 1990. Many deaf people claim disability benefits or services under present legislation for disabled people. Special education funds, which support students with disabilities in public schools, also support interpreters for mainstreamed deaf students and separate programs for deaf students. In discussing a Deaf friend's ambivalence towards using a "handicapped" discount on the subway, Padden and Humphries (1988) make the following observation regarding the awkward relationship between "disabled" and "Deaf":

"Disabled" is a label that historically has not belonged to Deaf people. It suggests political self-representations and goals unfamiliar to the group. When Deaf people discuss their deafness, they use terms deeply related to their language, their past, and their community. Their enduring concerns have been the preservation of their language, policies for educating deaf children, and maintenance of their social and political organizations. The

modern language of “access” and “civil rights”, as unfamiliar as it is to Deaf people, has been used by Deaf leaders because the public understands these concerns more readily than ones specific to the Deaf community. Knowing well the special benefits, economic and otherwise, of calling themselves disabled, Deaf people have a history, albeit an uneasy one, of alignment with other disabled groups. But as our friend on the subway reminded us, “disabled” is not a primary term of self-identification, indeed it is one that requires a disclaimer” (Padden & Humphries, 1988, p. 44).

As Lane (1995a) acknowledges, if cultural Deafness was redefined as a linguistic minority (rather than a disability), many of the currently available entitlements and services would no longer apply. Instead, culturally Deaf persons would be covered under civil rights laws and rulings, and educational provisions designed to support linguistic minority children could be applied to culturally Deaf children. What is not clear is where the lines would be drawn. For example, if separate schools were available for culturally deaf students, what definition would be used to determine eligibility and how would it be applied? Might someone identify themselves as culturally Deaf with regard to schooling, but later claim a disability status, or is the claim to a particular status made once and then maintained for a lifetime? How many people who consider themselves culturally Deaf would be willing to give up economic benefits and legal rights currently available to them as “disabled” citizens? These and other questions must be addressed if a formal change in status is adopted for any group of deaf persons.

SECTION THREE: ANALYZING THE “FIT” BETWEEN DEAFNESS AND DISABILITY

The focus in this chapter is the examination of deafness and disability as “same or different”. The three models of disability and deafness described in the first section can also be described as a continuum from same to different. The medical model is essentially a conformist model in that the emphasis is on encouraging and enabling the disabled or deaf person to conform to expected standards and levels of performance. The social construction model is an inclusion model, through which society is altered in ways that facilitate the integration of deaf or disabled persons into the social and economic mainstream. The political model is multicultural – disabled or deaf persons seek to discover and maintain a unique identity and culture while ensuring equal rights and opportunities.

In the second section of this chapter we examined points of convergence and difference between deafness and disability, and found considerable evidence to support both sides of the issue. So what’s the answer? Are deafness and

disability simply variations of the same theme, or are they fundamentally different experiences? Perhaps this question can be more easily answered by examining disability and deafness as multi-dimensional experiences, and by considering the question at three levels – that of the deaf community, the disability community, and the American community.

At the first level, there is tremendous diversity within the deaf community. As Bienvenu (1991) notes, of the 20 million American people with a hearing loss of some kind in America, only about two million are culturally Deaf, i.e. Deaf persons who “share the same language, norms and values”. Most culturally Deaf persons are deaf from birth or become deaf before acquiring spoken language (prelingually deaf), use ASL as a first language, support separate schools for deaf students, and participate actively in the deaf clubs. Persons who describe themselves as hard of hearing, advocate oralism, are postlingually deaf, support mainstream schooling for deaf students, and/or do not participate in the deaf clubs are generally not considered culturally Deaf. Age of onset of deafness, language preference, school experience, and parents’ hearing status all contribute to the way(s) in which a deaf person thinks of him or herself. When issues of race, ethnicity and gender are added to the mix, the heterogeneity of the deaf community is further underscored. While two deaf persons share the physiological condition of deafness, the similarities may end at that, or they may be built upon other shared characteristics or experiences, such as race, gender, schooling, and so forth.

At the level of disability, deafness is also both “same and different”. As noted in the last section, deaf and disabled people share many experiences and circumstances, but they also are quite different in significant ways. Those deaf persons who define themselves as culturally Deaf may see themselves as different from persons with disabilities. However, the larger community of deaf and hard of hearing persons who are not culturally Deaf may identify with the experiences and perspectives of persons with disabilities. It is also possible for deaf persons to incorporate both Deaf culture and disability culture within their identity.

At the level of American society, deaf persons are “same and different” in the same ways as are persons with disabilities. Both groups want access to quality education, opportunities for employment and career advancement, and the ability to enjoy the same level of resources and services as are available to all citizens; in this regard, they are the same as other members of American society. Their differences have to do not so much with the physical characteristics that traditionally have been labeled “disability” or “deafness”, but with the models within which these characteristics have been interpreted.

Same or Different? A Multi-Dimensional Perspective

Research on identity of deaf minority persons offers a potentially useful way of thinking about the relationship between deafness and disability. Foster and Kinuthia (1995) conducted in depth, open-ended interviews with 33 deaf minority college students (11 each African, Hispanic, and Asian American students). The broad purpose of the study was to describe the experiences of these students within their families and at school prior to their arrival on campus, as well as their experiences while at college. A subset of questions focused on issues of identity; students were asked to describe how they think about and define themselves, e.g. as black, deaf, male/female, etc.

Students' stories and explanations of who they are suggest that identity can be modified according to the demands of the situation. For example, a deaf Hispanic student said that at college he is deaf but at home he is more hard of hearing and Spanish. In his words, "Here [college] I think I am more deaf than at home. Because at home there are not that many deaf There I think I am hard of hearing But here I am deaf because [I] use sign language a lot At home, with my parents, I don't use sign language. I just speak with my voice and speak Spanish". For this student, communication and language circumstances were a determining factor in shaping identity.

In other cases, students' identities were created or permanently reshaped in response to new circumstances. For example, a deaf black student who came to college as a single mother found that she identified more strongly with other caucasian deaf single mothers than she did with black deaf friends who did not have children; while race and deafness were still defining factors in her life, parenthood had refocused her identity.

The circumstance of oppression or discrimination is a third kind of situation that shapes identity. One student said that he thinks of himself as "deaf first" because he feels he will be denied opportunities for employment because he is deaf. Another student said that she thinks of herself as "black first" because that is how others define her: "When I walk into the restaurant, they are looking at me because I'm black. Or, I'm going into the store, they follow me because I'm black, and they think I'm going to steal something".

Implicit in these students' stories is the idea that people have more than one identity. Gender, race, marital status, parenthood, deaf/ASL, deaf/oral – these are but a few of the core identities described by students. One or more of these identities is drawn out in response to the needs and demands of the situation. The Hispanic student is not a hypocrite or unsure of himself because he is "deaf" at school and "hard of hearing" at home; rather, he is adapting to the circumstances and opportunities presented by each situation.

In short, it was concluded that identity is fluid, responsive, and cumulative, changing according to the demands of the situation and evolving over time. This did not mean that the individuals interviewed lacked a “core identity”, or sense of who they are. Rather, their identity was multi-dimensional. In her discussion of cultural and language diversity and identity among deaf persons, Parasnis (2000) makes a similar point when she defines identity as “a dynamic concept, influenced by psychological, situational, and relational variables.

Is deafness the same as or different than disability? A multi-dimensional and dynamic interpretation of identity would suggest that *it is both*. Just as it is possible for a person to be both “deaf” and “hard of hearing”, it is possible for a deaf person to seek inclusion within one situation and segregation within another. A deaf person may choose to work from 8–5 with hearing people, where she or he uses a combination of communication strategies, including speech, writing, gestures and interpreters. The same person may then go to the local deaf club, or home to a deaf spouse, where communication takes place in ASL. Deaf parents may choose a separate school for their deaf child but encourage that child to attend a mainstream university. Deaf advocates may ally with disability advocates to seek passage of legislation, but otherwise distance themselves from Disability culture. A deaf woman who has never used a hearing aid may choose to get one when she gives birth to a hearing child because she finds with the device she is more likely to hear her child cry from the next room.

Implications for Disability and Deaf Studies

Areas of overlap as well as distinction between disability studies and deaf studies curricula should be addressed. For example, many if not most of the topics currently covered in disability studies courses have implications for deaf persons (i.e. race, technology, women, mental health, education, employment). However, it must be recognized that the interpretation of these topics may be very different for deaf people than for people with disabilities (for example, school inclusion). Other topics which are core to deaf studies programs, such as American Sign Language, may not be covered in most disability studies courses. Such gaps should be acknowledged and, where possible, students should be referred to courses or alternative resources for further instruction and information. In the long run, instructors may find it beneficial to devote one or more classes within the disability studies course to the topic of deafness, and to use this time with students to discover, describe, and reflect upon the various ways in which deafness is both “same and different”. Such dialogue may lead

to further conversations within the field of disability studies about ways in which we are all unique as well as the ties that bind us to one another.

Finally, disability studies curricula must acknowledge and incorporate deafness as both same and different. This includes recognition of the perspective of culturally Deaf persons that they are not part of Disability culture and the reasons for this belief. It must also include the myriad perspectives represented by the other 90% of deaf and hard of hearing people, including the belief by some that deafness is, indeed, a handicap under some circumstances. This does not mean that disabilities studies curricula should promote or support a definition of deafness as a handicap, only that they should recognize this belief as part of the broad mosaic of individual as well as collective identities of people who are deaf.

NOTES

1. The upper case "Deaf" is used in this paper to refer to deaf people who share a language, culture, and values, while the lowercase "deaf" refers to the audiological condition of not hearing. Similarly, the uppercase "Disability" is used to refer to a disabled persons who identify themselves in terms of a shared culture, experience, and values.

2. Elements of this discussion also appear in S. Foster, "Doing research in deafness: some considerations and strategies", in P. Higgins and J. Nash (Eds), *Understanding Deafness Socially*, Second Edition, 1996. Courtesy of Charles C Thomas, Publisher, Springfield, Illinois.

3. In his book *Handicapping America* (1978), Frank Bowe defines disability as "a condition of at least six months' duration that interferes with a person's ability to perform certain major life activities (p. 154) He defines handicap as "an interaction between a disability and a given environment" (p. 154) Thus, a disabled person may be handicapped in one setting but not in another. Critical to the difference between disability and handicap is the availability of appropriate accommodations and the attitudes of those involved in the interaction. Impairment is a definition of disability in which the interpretation of the individual's condition is negative, e.g. something is broken or a system has failed.

4. The notion of ASL as the "language of choice" rather than simply a convenient way of communication for deaf persons is critical because it underscores the connection between language and culture, i.e. in choosing ASL, culturally Deaf persons are making a statement about cultural affiliation and identity.

5. This is not to suggest that deaf persons have not organized for political purposes. For example, the National Association of the Deaf was formed in 1880 in direct response to the Milan Conference and the need to preserve sign language, and the National Fraternal Society of the Deaf was established in 1901 out of frustrations by many deaf people in their efforts to purchase life insurance.

6. Several colleagues who reviewed earlier drafts of this paper said it would be interesting to know the percentage of persons with disabilities who married other persons with disabilities. Unfortunately, I was unable to find this figure. However, I did

learn that disabled women are less likely to marry than non-disabled women or disabled men (Fine & Asch, 1988), while deaf women are more likely to marry than deaf men (Schein & Delk, 1974). Moreover, it was speculated that "disabled women who marry *after* onset of disability are more likely than similarly disabled men to have a disabled spouse" (Fine & Asch, 1988: 21); for deaf couples the situation is reversed, in that 88% of deaf males have deaf or hard of hearing spouses compared to 85.8% of deaf females (Schein & Delk, 1974).

7. Thomas Holcomb, Ph.D., is a faculty member in the Ohlone College Deaf Center in Fremont, CA.

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