

J. L.

Crucial Readings in Special Education

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3.2 Divided Society

Simi Linton

I have the right when I go out and pay good money for a meal to enjoy it. The sight of a woman in a wheelchair with food running down her chin would make me throw up. I believe my rights should be respected as much as the rights of the person in the wheelchair . . . maybe even more so, because I am normal and she is not.

In my opinion, restaurants should have a special section for handicapped people—partially hidden by palms or other greenery so they are not seen by other guests.

—excerpts from two letters printed in an Ann Landers column, spring 1987

No person who is diseased, maimed, mutilated or in any way deformed so as to be an unsightly or disgusting object or improper person to be allowed in or on the public ways or other public places in this city, shall therein or thereon expose himself to public view, under penalty of not less than one dollar nor more than fifty dollars for each offense.

—from the Municipal Code of the City of Chicago

It is in the formal and informal, the explicit and the tacit, the overt and the covert that society works to divide up the human community and oppress some of its members. The above example of public rules and private thoughts (revealed in the safety of anonymity) may not seem to have much force. Federal law prohibits such discrimination, and public expression of these sentiments would be scorned in many circles and the speakers branded as unsympathetic or uncharitable, not to mention unsophisticated. But the underlying ethos has not dissolved with shifting practices; it remains a virulent force with new manifestations.

As Young (1990) notes:

The objectification and overt domination of despised bodies that obtained in the nineteenth century, however, has receded in our time, and a discursive commitment to equality for all has emerged. Racism, sexism, homophobia, ageism, and ableism, I argue, have not disappeared with that commitment, but have gone underground, dwelling in everyday habits and cultural meanings of which people are for the most part unaware. (124)

Linton, S. (1998). Divided society. In *Claiming Disability: Knowledge and Identity*, (pp. 34–70). New York: NYU Press. Reprinted by permission.

To Young's comments I would add that in addition to the everyday habits and cultural meanings, there remain policies and practices that serve to control and marginalize disabled people. Unfortunately, these barriers to the integration of disabled people are often not fully visible, at least not to the untrained observer. They function like the "glass ceiling" that women come up against when attempting to advance in business. But it would be a mistake to say that the barriers that women or disabled people encounter are truly invisible. For instance, the policy to exclude women from private clubs where business deals are clinched might be made visible by looking at the by-laws of such clubs, or by testing the admissions practices. The practices within the clubs can be revealed by conducting research on the behaviors and habits of their members to find out how they transact business while seeming to talk about golf. Of course it would take extraordinary methods to expose all the structural inequities that exist in the business world and other significant arenas that privilege some groups' participation and success. Moreover, as Marx and others have instructed us, these local events are often controlled by forces beyond the purview of those acting at that site, making it even more difficult to gain access to the information (Gorelick 1996). Nevertheless, it is important to recognize that by call-

ing the barriers invisible we run the risk of implying that they are so amorphous and intangible that we can't document them and can't change them.

A watchful outsider might recognize some of the more obvious barriers that exclude disabled people from participation in society but may have the false impression that there are few hidden barriers. It may seem that if ramps are built to get into all the polling places, sign language interpreters are provided at public functions, and the Constitution is transcribed into Braille, we will have done away with the inequities. But redressing second-class citizenship, 66 percent unemployment, incarceration in institutions, and separate and unequal education will take more than these mechanical changes (Shapiro 1993).

Although an enormous amount of research is yet to be done to document the complex history of these practices and to catalogue their current manifestations, we can review what is already known about humans' response to disability to see that disability has been conceptualized and responded to in a variety of ways throughout history and across human cultures. It is not a singular history. There isn't, as some might imagine, a clear stream of progress from prehistory to the present moment. Nor is it accurate to valorize the United States and other Westernized countries for exemplary practices and an enlightened vision.

This chapter examines the variations in social arrangements that have existed throughout history and currently exist around the world. Of course, it is not possible to provide a complete history of humans' response to disability. Some significant examples have been chosen in order to demonstrate the variation and to expose some of the problems that have occurred in the documentation and interpretation of that history. Disabled people have existed predominantly as marginal figures, their contributions and perspectives are not generally noted. Researchers outside disability studies have not been actively interested in this history nor in examining the meaning and function of disability in the lives of the few well-known people with disabilities.

The disability history that does exist is heavily dominated by the perspectives of scholars from the United States and Western Europe, whether they are looking at their own country's practices or others', leaving even more obscure the perspectives from the remainder of the world. Further, these reports usually do not make differentiations along gender, class, or race lines; therefore, many of the statements made about "treatment of disabled people" are not truly for the whole population. The most fundamental prob-

lem, though, is that disabled people's voices are almost completely absent from this picture, and so the understanding of disabled people's place in these situations is filtered through the experience of people who have never been in that place.

VARIATIONS

Although there are variations across time and cultures in response to disability, there are patterns that can be traced. An article by Hanks and Hanks written in 1948 provides a useful starting point for organizing the available evidence into a typology or classification system. While their study, *The Physically Handicapped in Certain Non-Occidental Societies*, predates the formal presentation of social models of disability by some thirty years, it is focused on the social variables that structure participation of disabled people in selected societies. It is a strength of the report that they looked primarily at social participation rather than at treatment or care provided to disabled people, and that they looked to the social structure for the explanation of the degree of integration or participation of disabled people in each society rather than to the nature of the disability itself or the psychological makeup of disabled individuals. Astonishingly, they also in some instances point out class and gender differences in disability experience in instructive ways. There are also some limitations to their schema, to their interpretations, and to the data they looked to for evidence.

Hanks and Hanks analyzed practices in a number of cultures, with a particular interest in response to physical disability in "non-Occidental" societies. A limitation of their material, therefore, for the present analysis is that practices related to people with other disabilities are not included; relatively few countries were actually studied; and Westernized and/or industrialized countries are not included. The few gender and class differences they did note are inadequate to the complexity that exists, and, further, their descriptions fall short of the meaning that these differences have for the people they describe. Another limitation is that their conceptualization of response to disability into the five domains they chose limits the range of practices that can be studied. Therefore, I have added a sixth category and reworked some of the descriptive material to include an even broader range of data and more contemporary examples. In a number of places, I have indicated ways that a more explicit and differentiated scheme could be fashioned from the data and theoretical formulations that have emerged since their study. These caveats aside, the

Hankses' original categories, Pariah, Economic Liability, Tolerant Utilization, Limited Participation, and Laissez-faire, as amended, are described below, along with the sixth category, Active Participation and Accommodation that I have added.

1. *Pariah*. The first category, Pariah, is described by Hanks and Hanks (1948) as cultures in which disabled people are "denied all claims to succor by the protective group and [are] deemed a threat to the group itself" (13). I have amended this to read that disabled people are denied most if not all claims to succor and to rights by the dominant nondisabled majority and are deemed a threat to the group itself. This revision alters the category in three significant ways. The addition of "rights" and "dominant group" makes explicit the power differentials in these situations in which nondisabled people determine what resources, if any, will be made available to disabled people. I have eliminated the Hankses' term "protective group" because it assumes that protection is the desired behavior. Although the definition of *pariah* in many dictionaries is solely "social outcast," typical usage and other dictionaries also incorporate more active and virulent meanings, such as Merriam Webster's "despised by society." Throughout history there have been groups whose religious beliefs or social customs sanctioned practices that were harmful, and often lethal, for disabled people. Therefore, the practices discussed in this category reflect more than the passive meaning, that the individual is an outcast; rather, the examples support the stance of "casting out" or harming these despised members of society.

Denying or withholding resources or protection is one set of responses to disabled people deemed pariahs. Hanks and Hanks (1948) state that the practice of denying all protection and care is "most frequent in India" (13), where the family is put at risk by having a disabled member because its social position is thereby threatened. The family may deny the individual protection. However, a woman is told to care for, indeed worship, her disabled husband even if his family abandons him. Women with disabilities, it seems, would not expect the reciprocal response from their husbands.

Directly harming or killing disabled people is an even more aggressive means of managing the perceived threat. It is ironic that the Hankses, writing in the late 1940s, pointed toward India, when evidence of what was probably the most comprehensive example of systematic violence toward disabled

people was known. Granted their focus was on "non-Occidental" societies, but they wrote "most frequent in India" and other phrases in an absolute manner, implying its unequivocal status. Nazi Germany took specific actions to eliminate disabled people and succeeded in annihilating 200,000 "disabled men, women and children . . . 'Lebensunwertes Leben'—life unworthy of life—was the concept Nazi doctors used to justify their practice of direct medical euthanasia" (Shapiro 1993, 271). Disabled people threatened the idea of Aryan perfection, constructed around a very narrow band of acceptable behavior, appearance, and genetic makeup. (The contributions of the United States to the early eugenics movement on which Nazi practices were built is discussed in the next chapter.)

A most profound example of withholding care and "succor" can be seen in the United States, in the history of many of our institutions and asylums. In the early 1970s Geraldo Rivera described the conditions at the Willowbrook State School that were "not unlike Nazi deathcamps. At Willowbrook, Rivera told his viewers, one hundred percent of all residents contracted hepatitis within six months of entering the institution. . . . Many lay on dayroom floors (naked) in their own feces" (Trent 1994, 258). A more recent example, affecting people with a broader range of disabilities, is reported by Asch and Fine (1988, 23) from a *New York Times* article from 1984. "An inquiry into California's community care facilities for the mentally and physically disabled and for the elderly found that 'daily, throughout the state, residents of community care facilities are being sexually abused, beaten, fed spoiled food, forced to live with toilets that don't work.'"

There are varying reports on the degree to which infanticide has occurred in the past or still does. Scheer and Groce (1988) note that infanticide of disabled newborns is not commonly practiced in developing countries, despite popular beliefs to the contrary. However, a number of examples of disabled children being killed at birth or shortly thereafter have been documented. These practices, though, also target children not considered disabled by Western definitions, such as babies with extra fingers or twins. For instance, Nichols (1993) reports that among the Ashantis of central Ghana infants with six fingers are killed at birth and with "the Igbo and some other groups infanticide sometimes occurred following the birth of twins" (32).

Mallory (1993) describes how the Songye tribe of Zaire divides all children with physical anomalies into three categories: ceremonial, miserable, or faulty.

"Miserable children are those born with albinism, dwarfism, or hydrocephaly." They are not seen as human beings; rather, they are thought to be supernatural beings and are accorded "an inferior status in the tribe, and little is done to make their lives comfortable or meaningful" (18). The Igbo of Nigeria are reported to "tolerate" certain "minor birth defects" but other "abnormal babies are usually killed and thrown away by the Ebih priest" (Nichols 1993, 32). The practice of "throwing away," or abandoning babies on river banks or in the bush, is practiced by the Igbo with twins and by the Ashantis with "severely" retarded infants because both groups of infants are thought to be animal-like. Whyte (1995) reports that these practices have tapered off in recent times and that there is increased conflict between the parents, who often wish to have the infant live, and the will of the elders of the tribe, who may wish to conform to ritual practices. Ross (1983) reports that "infanticide in hunting and gathering societies was probably universally practiced in instances of congenital birth defects" and also notes that there are "ethnographic references to the ritual disposal of adolescents and adults when they had become physically disabled and were unable to be ambulatory or fulfill certain tasks." Ross later says that these actions are taken "only when selective pressures were beyond the control of the particular group in question" (137).

A recent report in the *Atlantic Monthly* on orphanages in China demonstrates how vulnerable babies born with disabilities are there. It should be noted that other infants are also vulnerable in those institutions, particularly girls. Anne Thurston (1996) reported that for years friends had been telling her "that severely handicapped infants—those with incapacitating infirmities requiring full-time care—are routinely allowed to die" (40). Other infants are placed in "dying rooms" as well, although it appears that the practice is more systematic and probably more generally accepted when the infants are disabled. A doctor with whom Thurston spoke, "a man of great compassion," pointed out that the "best of his people have suffered the most egregious persecution . . . [therefore] does it not follow that those of so little official worth—the handicapped and abandoned—should be allowed to die" (40). This statement is Thurston's paraphrase, and hence it is not possible to tell whether the word "official" as a modifier of "worth" is the doctor's view, Thurston's, or the government's. However, "the best of his people" is said straightforwardly and implies its opposite, the worst. Comments such as these come out in

public unchecked when the speaker assumes that there is consensus on the official worth of disabled people.

In the reports of Chinese and African practices, a number of explanations are provided for these practices that emanate from commonly held belief systems. For instance, the *Buddhist* belief that "a severe handicap [is] . . . evidence of a heinous crime in a previous life" and the Confucian belief that "a severely handicapped child would be incapable of fulfilling the immutable demands of filial piety and thus unable to behave as a proper human being" (Thurston 1996, 40) are mentioned. Nichols, in discussing the derivations of African practices, makes an important distinction between beliefs that emerge from what he calls "*pragmatic spirituality*" and those attributable to "*blind superstition*" (1993, 29). His objective is to take a more serious look at belief systems that have often been dismissed as "primitive" or "barbaric" and to demonstrate the humanitarian and practical responses evidenced in African cultures. It is ironic, and unfortunate, that a metaphoric use of *blind* is employed in this context, particularly because, in contrast to pragmatic spirituality, which is thought to reflect knowledge and utility, blind superstition is in "bondage to ignorance" (29). All these pragmatic and metaphysical explanations provide useful material for analysis, but a rigorous examination of the practices themselves needs to be made. Ritual "disposal" of disabled people and infanticide are murder and therefore individual acts, no matter what function they are serving and no matter what complex long standing imperatives they fulfill.

The recent debates about euthanasia, currently being called "physician-assisted suicide," and about prenatal screening and selective abortion in North America and in Europe have raised concerns about the "right to life" of disabled people. The Supreme Court in the United States is deliberating on the legality of physician-assisted suicide, and the issue is being debated throughout the press. Disabled people and allies, in demonstrations outside the Court in January 1996 and in other fora, have been pointing out that "suicide" implies a fully voluntary act, and for many disabled people and poor people there are coercive forces that act on their choices. Particularly in the climate of managed care, where the economic imperatives that guide a physician's choices are increasingly powerful, the supposed "expense" of disabled people's lives make us more vulnerable to coercion. Further, physicians are not reliable judges of the value and worth of disabled people's lives. Nat Hentoff (1997b) reports that Dr. Katherine Foley,

cochief of the Pain and Palliative Care Service at the Memorial Sloan-Kettering Cancer Center, said in an interview that "physicians consistently underestimate the quality of living for those individuals who are disabled."

For a number of years disabled people have been watching the Netherlands, where "Dutch doctors have been empowered to help patients kill themselves, and, increasingly, physicians there have been directly killing patients without being asked to" (Hentoff 1997a). Hentoff asked a television interviewer how the "Dutch people can justify not only this 'quality of life' killing of adults, which brings back memories of Nazi occupiers—but also the liquidating of 'defective' children." It is particularly horrible that today the Dutch appear complicit in these actions when just over fifty years ago, Dutch physicians gave up their medical licenses rather than join the Nazi medical association. A study conducted in 1995 revealed that "23 percent of the doctors interviewed reported that they had euthanized a patient without his or her explicit request," and in some cases made the initial suggestion that "death should be embraced."

Less egregious than murder but socially and personally devastating is the practice of ostracizing and vilifying members of a society. Two recent reports from Japan provide examples of behaviors that have existed and continue in many places in the world. The headline of a *New York Times* article by N. D. Kristof (1996) declares, "Outcast Status Worsens Pain of Japan's Disabled." Osamu Takahashi, now age forty-nine and the director of a center for disabled people in Japan, told the reporter that

[he] never went to any school and was hidden in the house from birth until the age of 26. While the rest of his family are together, he was served meals alone in his room. His family allowed him out of the house only about once a year, and then mostly at night so the neighbors would not see . . . [and] that view still survives in some households. (3)

The term *outcast* seems to have particular saliency for disabled people in Japan. Other people interviewed for the article described discrimination in housing, education, and employment but emphasized the pain and frustration of being social outcasts. S. Sesser (1994) reported in the *New Yorker* on the particularly painful experience that people who are HIV positive have in Japan. "With the sick and the disabled ordinarily feeling like outcasts, it's not surprising that

those Japanese infected with H.I.V. are the most reclusive of all" (64).

Disabled people around the world who are deemed pariahs by their own families and communities have lived through the terrible pain of being denied succor by the very persons to whom it would be most natural to turn. Practices ranging from withholding attention, food, love, and education to denying them life itself have been documented. For the most part the practices described here are not unique to that particular culture. Many disabled people around the globe have stories to tell of abuse and marginalization. As the rest of this chapter will demonstrate, casting out and vilifying disabled people is the extreme end of a long and complex continuum.

2. Economic and Social Liability. I've changed the Hanks and Hanks (1948) original category, Economic Liability, to Economic and Social Liability to permit inclusion of examples of disabled people's being seen as impairing the economic well-being, as well as the vitality and viability, of a society. Even if disabled people are not considered pariahs, those who are thought to bring harm directly to individuals or to the group, there are situations or cultures where disabled people are unwelcome because they are thought to drain resources or deflect attention from other needs. Included in this category are the more extreme examples, couched in survivalist rhetoric, that invoke a lifeboat image of a society abandoning the "weaker" members to aid the survival of the group. Responses to these imperatives range from containment and control to abandonment and annihilation, all enacted ostensibly to conserve resources and protect the interests of the majority. This section does not survey practices across different countries but, rather, traces liability themes by describing the emergence of modern approaches to disability from the seventeenth through twentieth centuries in the United States and Europe.

The modernist "solution" to disability was the institutionalization of disabled people and the medicalization of all responses to disability. These were understood to be benchmarks of progress in the modern era. There are at least two competing ideas at work here. One is the belief that in the modern, industrialized world scientific and technological competence, coupled with advanced humanitarian and moral development, would lead the way toward the highest level of care and of concern ever evidenced. However, those modernist ideals mean the society

would not tolerate being bogged down by those who can't keep up, who are thought to drain resources, or who remind us in any way of the limitations of our scientific capabilities. In both ideas, the issues of efficiency prevail, leading to actions taken to contain the perceived negative social and economic impact of disability on society, even when glossed with an altruistic facade.

In the early years of the founding of the United States, and during a similar time frame in Europe, there were few facilities where disabled people were housed or cared for in systematic ways. Disabled people lived in their communities and occupied roles ranging from shoemaker to town fool to despised outcast. Their roles and degree of acceptance depended on a number of factors, including type of community, whether rural or urban; nature of the disability; status of the family; and gender, race, or personality of the individual. Paul Starr (1982) writes that "in the colonial period, the mentally ill, along with other classes of dependents, were treated as a local responsibility, primarily within their own or other families" (72). Early in the history of this country, individuals who would today be labeled mentally retarded were absorbed into communities with varying degrees of acceptance and support. Before the advent of large institutions, there were a few places, such as convents, where groups of disabled people were housed. What is apparent is that whatever ways disabled people were accommodated, the response was local and informal. For some disabled people, these situations were relatively comfortable. However, because of the idiosyncratic and arbitrary nature of these accommodations, disabled people were more likely to be ostracized than they were to be functioning members of the community. Further, even if work and participation in religious activities were possible, they may not have had opportunities for friendship, love, and intimacy. More systematic responses were to come, with varying outcomes for disabled people.

From the seventeenth through the twentieth centuries, a number of economic and philosophical factors affected community life for disabled people. Fraser and Gordon (1994) describe a transformation in policies for those in need and, moreover, in the whole idea of "dependency." America imported from England the model social legislation embodied in the Poor Relief Act of 1601 and it "did more than influence American laws—for the first 150 years of the colonies' existence, it was American law" (Groce 1992, 7). The

act acknowledged a responsibility to "disabled in need" but with a clear distinction made between those who were deemed worthy of such help and those who were not (7–8). The act may have given some disabled people more consistent financial support and relieved families of some financial responsibilities, but it also functioned to make more rigid the dividing lines between those for whom dependency was "deemed natural and proper" and those for whom receiving assistance was a source of shame.

During the seventeenth century, dependency on public assistance became more stigmatized. Whereas in the early days of the colonies "dependency" was considered a social relationship between one group and another, for instance, between workers and land-owners, increasingly "dependency could also designate an individual character trait" (Fraser and Gordon 1994, 315). A differentiated reading of dependency along gender and race lines emerged: women and the "dark races" were deemed acceptable as dependents, but it was considered shameful for white males to accept public assistance. Further, "dependency was deemed antithetical to citizenship" (315), which was also related to race and gender, and to disability. The condition of dependency was considered acceptable by the dominant majority for some groups, but it deprived recipients of the rights of citizenship and forced people to appear helpless in order to insure continued receipt of benefits.

America's glorification of independence has not served disabled people well. Individual worth came to be increasingly judged in terms of financial and social independence, a goal very, very few disabled people, nonwhites, and women could reach.

In the nineteenth century, there was a shift from the belief that disability was caused by supernatural agency¹ to a biological explanation that held that treatment, or some form of rehabilitation, was the logical response to disability (Longmore 1987). That shift marked the birth of an enormous "care" industry and along with it a variety of institutions, asylums, and state schools. Following the Civil War, a more comprehensive generalized approach to dealing with people in need of support developed that took the financial burden off families and communities. Trent (1994) reports, "[T]he shift from local to state responsibility for many groups of the disabled poor—the mad, the blind, the deaf, and the delinquent—[and] care for feeble-minded people became part of a response to rapid changes in the

social and economic fabric of American life" (39). Contributing to medical and state intervention were the growth of cities and the mobility of families. The population density in cities resulted in "a higher concentration of the insane . . . and a greater demand for order and security" (Starr 1982, 72). Trent also traces the development of a medicalized response to people with mental retardation in the United States and the birth of orphanages, asylums, and state-operated schools. These appeared throughout the country in the early eighteenth century; however, most would not admit children with physical and mental disabilities (11).

Specialized institutions and residential schools emerged with varying ideas about the people who lived in them and their needs. In the United States, there came to be more and more institutions organized around a particular type of disability. Within institutions, a number of notions shaped goals and practices. The most significant for disabled people was the increasing influence of medical personnel and practices. Although medicine didn't overtly claim expertise in reducing the economic liability posed by disabled people, it did corner the market on attempts to contain the perceived negative social impact of disability. This is most clearly seen in the growing influence of medicine on the response to mental illness and the shift from the mid-nineteenth century to the early twentieth century from custodial care of people with mental illnesses to belief in the efficacy of prevention and cure. Although superintendents of custodial institutions often had medical training, their work came to be seen as policing and restraining people. The medical establishment launched attacks on asylums, asserting their practice was unscientific because they were offering custodial care with no proven ability to treat or cure.

Adolf Meyer led the "mental hygiene" movement, a program that elevated the role of psychiatrists in not only treatment but prevention. The institutions that emerged in the twentieth century became teaching hospitals and research centers. Along with this trend in institutional care, spurred by a new orientation to scientific progress, came a belief in aftercare, which "looked not to the chronic, but to the curable patient, not to custody but to *adjustment*, not to continued dependence but to *independence*" (Rothman 1980, 313). The practices were reminiscent of the way some communities had responded to mental illness before the growth of institutions.

Of course, had this push toward independence and productivity for people with mental illness and other disabilities been successful, and had the government assured the type of support and equality of

opportunity that would have allowed disabled people to live in the community, the history of disabled people in the twentieth century would look much different than it does. Some of the innovative medical interventions and growing expertise might then have been coupled with a commitment to independent living, active participation in the community, and, possibly, with concern for rights and equality. Instead, institutionalization and medical control became the norm for many disabled people.

The idea that disabled people are, in an absolute sense, an economic and social liability is rarely challenged. The belief that disabled people impede progress or increase the vulnerability of a society, particularly when it is under siege, has never been tested, and certainly has never been tested in a society that works to maximize the productivity and participation of disabled people. The financial stability of society does not seem to be the factor that determines greater degrees of acceptance and participation. Indeed, Hanks and Hanks (1948) conclude their discussion of this category by commenting that economic considerations alone don't determine response to disability. They remind us that although some of the groups they discuss resort to infanticide or other means of eliminating disabled people when there are scant resources, "the Paiute of the Great Basin of North America, who had an almost equally precarious margin of existence, neither practiced infanticide nor abandoned their disabled . . ." And the Australians, who "had a slim margin of surplus" did practice infanticide but "seem not to have disposed of the physically handicapped" (16).

In the current climate in the United States of managed health care, there is a deep fear among disabled people that our lives will be weighed on an economic scale. In Michael Bérubé's (1996) book about his family's experience of having a child born with Down syndrome, he speaks poignantly of that fear:

Among the many things I fear coming to pass in my children's lifetime, I fear this above all: that children like James will eventually be seen as "luxuries" employers and insurance companies cannot afford, or as "luxuries" the nation or the planet cannot afford. I do not want to see a world in which human life is judged by the kind of cost-benefit analysis that weeds out those least likely to attain self-sufficiency and to provide adequate "returns" on social investments. (52)

3. *Tolerant Utilization.* One can infer from the examples provided under the Hankses' (1948) category

Tolerant Utilization that they recognized situations in which disabled people, although often marginal figures in the society, are allowed to participate to the extent that they have the ability to fulfill certain roles and duties designated by the nondisabled majority as necessary. Disabled people's actions therefore are at the will and bidding of the nondisabled majority. For instance, during World War II disabled people worked in record numbers because so many "able-bodied" people were at war. During this time women (both disabled and nondisabled) were also employed in positions never before open to them. At the close of the war, these groups returned to their previously low levels of employment and to the restricted range of positions they were allowed to occupy.

Another example of disabled people being utilized as needed by the society are situations in which they are considered more useful or practical in certain roles than nondisabled people. For instance, the utilization of hearing-impaired and deaf workers on assembly lines where noisy machinery is used or of people of short stature in tight spaces where larger workers cannot fit. Although gainful employment is always desirable in a drastically underemployed group and there is a certain peculiar logic to these solutions, given the economic vulnerability and low social status of men and women with disabilities, these situations are ripe for exploitation. Further, the particular health and safety issues for these workers and the lack of control or free will in such situations make them highly dubious opportunities.

Disabled people have also served at the dominant culture's pleasure as fools and jesters in a royal court, and in such social institutions and rituals as freak shows and carnivals. People have been put on public display in circuses and other more sedate institutions, such as museums and medical facilities. (Bogdan 1988, 1996; Thomson 1996). A man described as the "Elephant Man" and a woman called the "Hottentot Venus" were put on view in medical and scientific settings, as well as in commercial venues. People have worked in these areas out of economic necessity or because they were under the "care" of medical personnel and had little opportunity to pursue other goals. Either as scientific specimens or amusements displayed for profit, people with disabilities were denied basic rights and freedoms. Although the large buttocks and genitalia of the "Hottentot Venus" are not disabilities by most current legal and typical definitions, her body and that of the "Elephant Man" were considered pathological by social standards.

A final example boldly illuminates the utilitarian and exploitive nature of some people's ideas about disabled women and men, and about women in general:

When geneticist Sharlene George was interviewed for admission into a graduate program at Stanford University in 1967, the department chair said: "Miss George, do you know why I'm interviewing you? It's because this year I'm reduced to the lame, the halt, the blind, and the women." (Todd 1984, 44)

The next three categories, Limited Participation, Laissez-Faire, and Participation and Accommodation, are presented together and then used to discuss the continuum in educational practice in the United States from the seventeenth century to the present.

4. *Limited Participation.* The category Limited Participation is the least specific in the Hankses' typology and the examples provided are the most ambiguous, yet I find the term useful to describe situations in which disabled people's roles and status are largely derived from their ability to be productive in terms of the standards set by the dominant majority. This idea is based on an individual model of disability, the idea that it is up to the individual to demonstrate worth and competence. It promotes a false sense of acceptance because the norms and standards of the able-bodied majority are imposed and held up as the ideal to which all should aspire. Whereas the previous category, Tolerant Utilization, speaks to the society's control not only of criteria for performance but of domains in which competence can be demonstrated, Limited Participation indicates the society's willingness to accept a disabled person among its ranks in any domain in which she or he can "keep up" with the nondisabled.

5. *Laissez-Faire.* In the Hankses' (1948) description of their last category, Laissez-Faire, "a steadfast relation to the protective group, despite handicap," is observed and "the obligation of the extended family to shelter and provide for its unfortunates continues, whether they are able to give their labor or not" (18-19). I've eliminated the terms "protective group" and "provide for its unfortunates," two ideas that do not capture the more complex relations that occur among disabled and nondisabled people, and propose instead that the category include situations in which relations between nondisabled and disabled people exist, and where the family and community provide varying degrees of support for disabled people, whether they are able to work or not. Although in such situations the society does not overtly exclude

disabled people, it does not work toward accommodation, social justice, and equity with respect to them.

I am proposing that the idea of noninterference implied by the term *laissez-faire* applies to the social structures and not to specific responses to disabled people. Indeed, in such situations there may be various types of concern displayed for disabled people and interventions provided, yet if the norms of the able-bodied majority are centered and held up as the ultimate goal of all people, and the society makes no effort to reconstruct its goals or acceptable means of achieving them to reflect a broader range of citizens, the society has adopted a *laissez-faire* approach to disability. In such situations, the dominant group decides what disabled people need and attempts to meet those needs but does little to engage with disabled people as a constituency to work together to set the terms of accommodation. Disabled people then are left in the unenviable position of having to keep up with norms and standards but with no opportunity to shape them.

6. *Participation and Accommodation.* I've added the last category, Participation and Accommodation, to the Hankses' typology in order to report on the moments and places in which a proactive stance is evident toward the equitable participation of all members of the society. These are admittedly rare events, but there are some examples of concerted efforts to accommodate all members of the group and to adapt the procedures and standards typically imposed to reflect a range of abilities, interests, and needs. This does not mean lowering standards in an absolute sense; it means that greater flexibility is evident and a broader range of objectives are set. These actions are based on moral, practical, religious, and/or rights-based approaches to full participation of all members of society.

Throughout the history of the United States, education for disabled children has assumed many forms, from complete denial of formalized instruction to a few recent examples of exciting, well-informed, and inclusive classrooms where disabled and nondisabled children learn together in cooperative groups designed to maximize the participation of all children in the learning process. Between these extremes, disabled children have experienced a variety of learning environments.

There are segregated settings, including classrooms in institutions; specialized residential and day schools, designed either for children with specific disabilities or for mixed disability groupings; and sepa-

rate special education classrooms within a general education school. A variety of other types of placements for disabled children have emerged since the 1975 passage of PL94-142, "which guaranteed an education for the nation's eight million children with disabilities . . . in the least restrictive environment, that is with nondisabled children whenever possible" (Shapiro 1993, 166). These options include the common practice of placing some children who are identified as "special education" students in a general education class for one or two periods a day, or, for a few children, in those classrooms for whole day, if they can keep up with the academic curriculum. This practice of incorporating students in general education for part or all of the day is generally known as "mainstreaming," even though that is not a legal term. The total integration of all disabled children in general education is known as "inclusion" and exists currently in a number of isolated schools and in a few school districts around the country. In inclusive schools all children attend their neighborhood school, and are placed in classes based on age rather than on test results, evaluation, diagnosis, or past performance. Although inclusion is a very recent project of schools, there has not been a straightforward historical march from complete denial of education for those considered outcasts or pariahs through to totally inclusive and integrated classrooms.

The education system throughout the history of the United States exemplifies the range of responses demonstrated in the six categories presented in this chapter. The three categories just presented, Limited Participation, Laissez-Faire, and Participation and Accommodation, are particularly useful in distinguishing among the recent approaches to educating disabled children. Although the connections between the Hankses' typology and the educational practices described here are somewhat forced, I will describe how the ideology underlying each of their categories might lead to particular educational practices. When disabled people are considered pariahs, education, if provided at all, is aimed at containment and control. It might also have a taming function: to civilize creatures seen as not quite human. Any of the general goals of education—intellectual development, acculturation, employment, or preparation for participation in the democracy—would not be considered useful or worthwhile for people thought to be a threat to society, or incapable or unworthy of citizenship. However, to the extent that education is thought to decrease the dangerous, unwanted characteristics of disabled people, then it would be conducted in a situation isolated from oth-

ers, with goals of social control and order imposed rather than individual enhancement. These agendas were more obvious in institutions and asylums of the past, but I am not convinced that the ideology has disappeared. At any given moment, whether in an institution of the eighteenth or twentieth century, or a general education school today, the idea that disabled people are to be controlled can influence a number of different types of educational initiatives.

When education is guided by the idea that disabled people are Economic and Social Liabilities, then instruction will be geared toward decreasing the drain. Indeed, any educational intervention, short of the most proactive, rights-based approach to the education of all children, can be seen as responding to a need to reduce the economic and social burden disabled people are thought to represent. Rather than see the mission of education of disabled children in terms of intellectual and social development, preparing them to partake in the rights and pleasures of citizenship, the orientation that guides this approach is more focused on vocational training and on the tools and skills needed to become productive and self-sufficient. Similar interpretations have been made along class and race lines of the imperatives that drive education.

These liability themes emerge in, debates over what is the most cost-efficient means of educating disabled students. When moral and pedagogically based arguments for inclusive education are presented, they are often countered by economic arguments presented at school board meetings or in legislative bodies about the drain that educating disabled children is on community resources. However, the concerns raised about allocating resources to disabled children's education are based on local and immediate economic analyses. Broader, long-term analyses are often not part of these discussions, thereby bypassing recognition of the long-term consequences of denying children equitable education and the long-term gains that could be realized from an educated and prepared cadre of disabled children. In addition to the economic liability themes, concerns are also raised about whether the presence of disabled children in a general education classroom deflects attention from the needs of the nondisabled children. Each of these is a practical problem but also an ethical problem. My purpose here is to uncover the ethos that drives the decisions.

The values that underlie the Tolerant Utilization approach may subtly influence a school toward preparing disabled people to fulfill the functions that

the nondisabled majority are in need of. Recall that in this category are the situations in which disabled people, though treated as marginal figures in the society, are incorporated as needed if they have the ability to fulfill certain roles and duties designated by the nondisabled majority as useful. Therefore, pedagogy and curriculum are not guided by a concern for equality of opportunity but, rather, a utilitarian vision of educating disabled people. Special education classrooms, institutional settings, and sheltered workshops whose curriculum is influenced by this restricted and stereotyped vision of appropriate roles of disabled people qualify as examples in this category.

The categories Limited Participation and Laissez-Faire apply to situations in which standards for disabled people's performance are set by the dominant majority, and it is up to the individual to demonstrate worth and competence in terms of these criteria. This description could apply to schools that have mainstreaming programs for some disabled children and separate special education classes for others. Children with physical disabilities or sensory impairments may be mainstreamed for a few or all periods a day in general education classes if they can keep up with the academic level of the class. In settings such as these you often see students popped in and out of classrooms, put into a general education reading class if they show skill in this area but returned to the special education classroom or to a resource room if their skill is not considered equivalent to the general education students.

Some schools with mainstreaming programs have created wonderful, innovative programs to incorporate some of the disabled children into their general education classes. These programs provide more systematic interactions between nondisabled and disabled children, and the school provides support for some disabled children in more integrated classroom environments, even if the disabled children are not able to engage in or complete all the same tasks that nondisabled children can. Disabled children are eligible for such programs if they can keep up in most academic areas with the children identified as nondisabled. If they are not able to meet those requirements, segregated specialized education is provided, designed on a priori decisions made about their academic and social capabilities. Although the class or the school does not overtly exclude disabled people, it does not work toward full accommodation or equity with respect to disabled children.

In situations such as these, the basic structure of schools and classrooms remains unchanged, but some disabled children are shifted into general education

as long as they can keep up and their presence results in minimal alteration of the prevailing structure. The children's welfare may be of great concern to the school and the community, yet the vision of what can or should be done to create a more equitable environment is limited.

My objective here is not to indict the much-maligned special education teachers or programs. There is probably as broad a range of quality of education in general as in special education. The point is that mainstreaming and other moderate solutions are token programs that cull from the special education rosters the children who are most like the "mainstream." The system places them in classrooms where their presence is contingent on their behaving as much like the nondisabled children as possible. If drooling or having spasms or a speech impairment is not within the school's or the district's criteria for acceptable behaviors for mainstreamed classrooms, the child will be locked out of general education. This places the mainstreamed children in the awkward position of having to look and act as nondisabled as possible to maintain their position in general education and, as a result, it marginalizes even more the disabled children who can never play those parts. Further, and rarely discussed, mainstreamed children lose the opportunity to be with other disabled children. Mainstreaming doesn't erase the line between disabled and nondisabled people; it just draws the line between acceptable and not acceptable a little to the left or, if you're sitting on the opposite side, to the right.

For the past ten years in particular, the practices in most school districts have hovered between those whose overt structure resembles the Limited Participation and Laissez-Faire models. The other ideas, that disabled people are pariahs, social and economic burdens, and people to be utilized in society if and when they are needed, filters through educational discourse in more covert and intangible ways.

Recall that the distinguishing features of the last category, Accommodation and Participation, are that a proactive stance is taken toward equitable participation, and where procedures and standards are adapted to include everyone. The newest model of education, full inclusion, is the closest to such an accommodating environment. It differs from all the categories above in that in its most thorough and successful forms, all children go to their neighborhood school and all are incorporated in general education classes with appropriate supports and accommodations. The pedagogical practices and curriculum are designed to reach a broad range of children, and in-

tegration and active participation are goals the school is committed to. Whereas the practice of mainstreaming has been restricted primarily to children with physical disabilities and sensory impairments, the inclusion model incorporates all children, whatever their disability, in a general education classroom. Therefore, children with mental retardation, autism, or mental illnesses, those who are typically the most sequestered of all children, participate in the learning and social activities of inclusive classrooms. This is a startling idea for many people, particularly if they have never seen it in action. In classroom environments such as these, the criteria for demonstrating competence may not be the same for all children, but together the group tackles the subject matter and each child engages with it in a manner consistent with her or his aptitudes and needs. Goals and standards are shifted not downward but out, to a more flexible and broader means of demonstrating competence. The burden to "keep up" is shifted off the individual student, and the whole classroom environment shifts in its overall procedures and expectations to maximize learning for all.

The report of the National Center on Educational Restructuring and Inclusion (1995) on the status of inclusive education in the United States provides qualitative data on the benefits and problems in the transformation of schools to inclusive sites. Multiple examples underscore the positive transformations in the behavior and learning patterns of disabled students who have been transferred from special education classrooms to inclusive ones. Students who had previously required a great deal of adult intervention to sit still, to be quiet, to focus on lessons and not distract other students appear to respond to peer pressure to behave, and teachers are reported to spend much more time on instruction than on "parenting" behaviors such as "setting and enforcing guidelines of appropriate behavior" (226). An example from Burbank, California, describes one way that a school accommodated children who are deaf. The school draws children who are deaf from a wide area and, as a result, from one-third to two-thirds of the students in any given class are deaf. The regular school curriculum is maintained by using a team-teaching approach (one general education teacher and one teacher trained in special education, both fluent in sign language). All students participate in the same classes and recreational activities, with a high degree of social interaction among deaf and hearing students. The district report indicates that "there is no isolation of the deaf students, in the class-

room or playground. Hearing students sign . . . and at the eighth-grade graduation ceremony, the three hearing students who were chosen as speakers (the fourth was deaf) each signed their speech" (39).

Inclusion is not an educational plan to benefit disabled children. It is a model for educating all children equitably. The concept of heterogeneous grouping is supported by data from studies of detracking,² which indicate that the benefits of detracking accrue to all children. The benefits for the nondisabled children are not solely that they learn tolerance and acceptance. Although I don't want to minimize the importance of that lesson, the benefits are broader than the moral lessons such exposure can offer. For instance, when nondeaf children learn sign language, they are not only exposed to a second language, rare these days in most elementary schools but come to understand something about language itself and how it functions in human experience. The presence, let's say, of children with mental retardation in a classroom not only helps the children who have never had such exposure see the disabled children as complex human beings, recognize their strengths and weaknesses, and learn from their abilities but teach all the children how to interact to solve problems and about the range of ways that people approach a task. The children who learn more slowly can pick up cues from children who have mastered a particular domain, and the children who have mastered it can benefit from explaining it, paraphrasing and highlighting important points, and also, significantly, can benefit from watching the steps that the learners go through in mastering the material. A range of types of learners in the classroom provides teachers with many "teachable moments," the occasions when the spontaneous curriculum that arises in classroom interactions enriches learning.

I want to resist the impulse to overromanticize inclusive education. These described benefits don't always get realized. Inclusion has not been an unmitigated success wherever it has been implemented. Insufficient teacher preparation, overcrowding, and understaffing can interfere with the best of plans. Further, this plan for integrated environments in schools is taking place in a society that is far from integrated. Neither the children nor the teachers and parents have much experience with integrated communities. There have been instances where disabled children have been disruptive, where nondisabled children have rejected disabled children and they remain isolated in the classroom, and where teachers are overwhelmed and underprepared, and resent teaching in this type of heterogeneously grouped

classroom. Those problems may always occur, although there are certainly ways to decrease them.

Although integration is a goal of the disability rights community in education and in society as a whole, it does not stem from a valorization of the nondisabled, nor should it be read solely as a reaction to the quality of special education. "Normalization" is a spurious goal and not a useful way to think about the push to inclusive education. Herbert Kohl (1994) makes a similar point about the misinterpretation of the *Brown vs. Board of Education* decision when he notes that "the specific wording of the decision—'Separate education facilities are inherently unequal'—has racist implications," and he then distinguishes between involuntary and voluntary segregation (92). He reports on the high quality of teaching that occurred in many all-black schools.

What is wrong with special education, then, is not that the quality of instruction is necessarily inferior or that there are only disabled children in the classrooms. What is problematic is that these are often isolated, stigmatized classes, and that placement in special education is not voluntary. Segregated special education is bedeviled by the stigma that all members of the school, whether consciously or not, attach to the designation. All the children in the school, the staff, and parents know which classes are special education classes. No matter what kinds of overt lessons are taught at the school about respect for difference or other such seemingly committed agendas with weak impact, the hidden curriculum, the stronger message, is that children in special education are different, incompetent and unsavory, and, because of their isolation, easily avoidable. Expectations that the school, the disabled and nondisabled children, the parents, and the teachers have are inevitably lowered by these designations. Most damaging of all, the negative expectations are assimilated and internalized by the disabled children with devastating long-term consequences.

Segregated education is not inherently worse than integrated education because it is inhabited by disabled children. It is functionally worse because it is a restricted environment, with classes so small that the benefits of individualized instruction are often overshadowed by the limited types of interactions children can have with one another, and often by the dominance of adults, who may interfere with children's opportunities to learn from and with one another. Children in special education may learn a great deal. Indeed, there have been wonderful special education classes with dedicated and knowledgeable teachers, but as

Jeffrey Libby, an integration-support teacher for an inclusive elementary school, points out, "One of the biggest arguments against inclusion . . . is that disabled students can acquire more skills within an isolated setting . . . but you teach things in isolation, and they're only good in isolation" (Casanave 1991, 41).

Although integration is sought for the breadth of educational opportunities offered and other advantages, dismantling special education will, unfortunately, diminish disabled children's opportunities to grow and learn around other children with disabilities, which gives them the opportunity to shape this essential part of their identity in the company of others who share their experience. Children with disabilities are hungry for role models, and other children may be the only disabled people in a child's life. Exposure to other disabled children's adaptiveness, understanding of their social position, sense of self, ability to negotiate in the world, and basic information make these friendships critical in development. In an inclusive setting there may be only one or two children with disabilities in a classroom.

School districts that support inclusion are among the most consciously rendered participatory and accommodating environments known, yet there have been other moments and places in the world where integration has been spotted. For the most part these have been more spontaneous, chance events rather than purposefully constructed environments, and the accommodations are usually not for all disabled people, just groups who achieve certain significance in the culture. It is critical that these be noted. They speak to the human capacity to construct disability very differently than it usually is.

One of the most thoroughly investigated environments is described in a landmark study conducted by Nora Groce (1985) and reported in her book *Everyone Here Spoke Sign Language*. It is an ethnohistory of Martha's Vineyard, where, for more than two centuries ending in the 1950s, a high incidence of hereditary deafness existed. Rather than focus on the condition itself, Groce focuses on the accommodations that some communities on the island made to this subgroup of their population. The deaf and hearing residents lived and worked together as equals, and, as the book's title suggests, most people on the Vineyard were fluent in a signed language that evolved there. It should be noted that although the proportion of deaf residents was larger than usual, in the course of the three centuries in which this hereditary phenomenon occurred only about 72 people with hereditary deafness lived on the island, one in

every 155 people; the typical ratio in the United States in the nineteenth century was one in every 5,728 people. Therefore, the deaf on the island were significantly more proportionately, but the use of sign language by the whole community was in response to a rather small absolute number.

In interviews with members of the community who could remember the time when the deaf residents were still around, what comes across most vividly is the matter-of-fact way that they spoke of their deaf neighbors, and of their own accommodation to their presence. Groce (1985) notes that "the community's attitude can be judged also from the fact that until I asked a direct question on the subject, most of my informants never even considered anything unusual about the manner in which their deaf townsmen were integrated into the society" (51). But a reporter for the *Boston Sunday Herald* knew there was something unusual occurring there. Groce quotes an 1895 story:

The kindly and well-informed people whom I saw, strange to say, seem to be proud of the affliction—to regard it as a kind of plume in the hat of the stock. Elsewhere the afflicted are screened as much as possible from public notoriety. But these people gave me a great lot of photographs, extending back four generations. These pictures of people who have never spoken a word from the day of their birth, create the impression of the invasion by deafness of what might otherwise have been a wonderfully perfect type.

The reporter presaged the deaf pride movement by almost one hundred years and displayed some understanding of the social construction of disability. However, the ableist notion that the deaf people would be perfect if not for their impairments and a later comment that "the mutes are not uncomfortable in their deprivation" (52–53) reveal the limitations of the reporter's insight.

How would a reporter today approach a story on a similar but more circumscribed environment, for instance, the Burbank, California, school, discussed earlier, where hearing and nonhearing students learn and play together and where both groups are fluent in sign language? Would she or he frame the subjects as less than perfect, albeit valiant and plucky, and the hearing kids as generous and good-spirited? Paint the relationships between the two groups in sentimentalized colors? Glorify the accomplishments of the deaf children? Or might a reporter today have the sophistication and insight about disability issues to focus on

how an accommodating environment structures equality and motivates both groups to work together utilizing a range of communications media that allows full participation of everyone? Even if a reporter did have that sophistication and insight, she or he would have to contend with the overwhelming tendency of most news stories today to go for the uplifting human interest story rather than an analysis of the structural elements that determine interpersonal relationships. This is true of the media in general, but in the case of disability, the likelihood is magnified a thousand times.

Representations of disability and the representations of disabled people's place in society are largely in the hands of people schooled in a particular vision of disability, one that is saturated with deterministic thinking and characterized by maudlin and morbid sentiments projected onto disabled people's experience. The insistence not just that disability is an unfortunate occurrence but that disabled people are, perforce, "unfortunates" seeps into most reports on the disability experience. Insiders' reports of disability, as seen in some of the best of the disability studies scholarship and in such publications as the *Disability Rag* and the *Mouth*, present a different perspective.

The Martha's Vineyard study also stands in contrast to typical records of disabled people in society because it documents a Participatory and Accommodating environment, focuses on social determinants, and is comprehensive. The dearth of such reports raises a number of questions that I address below. Have there been no other such environments? Does the absence in history of similar environments indicate the impossibility of such integration and equity? Are researchers not interested in such social patterns? Do researchers lack the theoretical tools with which to evaluate such behaviors and practices?

I believe there have been and are places and moments where more equitable and integrated environments are seen. They are not ideal; indeed, Martha's Vineyard is far from ideal because the accommodation made to deaf people did not extend to all disabled people. These are places where the nondisabled center and dominance shifts and greater degrees of accommodation are evident. John Hockenberry (1995) describes the neighborhood around Israel's most famous acute trauma facility, at Tel Hashomer Hospital, where most people who were wounded in the wars or in automobile accidents go for rehabilitation. It seems the disabled men (it is not clear where disabled women go) stay on in the neighbor-

hood after they leave the hospital, and Hockenberry, a reporter for National Public Radio and a wheelchair user, noted a concentration of houses with "newly built wide doors, ramped entrances, and freshly paved driveways," quite different from most Israeli neighborhoods. The area, though, was "something of a cripple ghetto, the only place in Israel where I would regularly see people in wheelchairs on the street" (236).

Anyone who has ever visited a well-run independent living center³ would witness an environment consciously rendered to accommodate all people. In addition to the offices themselves, in the immediate neighborhood of these centers, you are more likely to see ramps to get into stores, accessible bathrooms in local restaurants, and possibly menus in Braille. In some instances, the independent living center has had a strong impact on local policy.

Berkeley, California was the site of the first independent living center in the country (incorporated in 1972), and is notable for its history of strong activism and high degree of local impact. Anyone with an interest in such phenomena would notice the curb cuts on every corner and the ramps into buildings. When I first visited Berkeley in 1975, what was even more striking to me was the degree to which disability had become such a common feature of the landscape that I could move about casually without causing a stir. People, it appeared to me, did not stare nor did they glance and quickly avert their eyes. People were, in general, neither rude nor overly solicitous. The shifts that had occurred in the physical and communications environments, and the strong presence of an active disability community have these kinds of effects on the interpersonal environment.

Granted, there are very few places like independent living centers and their environs where disabled people have much autonomy and freedom of movement. Only a few other examples come to mind. One is some of the newly designed areas in the National Parks System, where disabled people and nondisabled people have worked together to make the environments accessible. Another is a small, rustic resort I visited in Byron Bay, Australia, run by disabled people in a place where pleasure and good times are the order of the day. Other places include meetings of disability rights groups or disability studies conferences.

These places are remarkable for disabled people. They differ from most of the places encountered, in which inequities, discrimination, and marginalization are more likely to occur. These places are so radically different from typical experience and yet so

clearly possible that they remind us of the absence of will to create such environments everywhere. Thinking about this situation brings to mind a study reported in the *New York Times* Science section a few years ago. The article (Wilford, 1994) reviewed the results of a two-year investigation by an anthropologist of the sparsely populated island of Vanatinai near Papua New Guinea. Its front-page headline read "Sexes Equal on South Sea Isle." Dr. Maria Lepowsky reported that a unique social arrangement exists: men and women live and work as virtual equals. "It is not a place where men and women live in perfect harmony and where the privileges and burdens of both sexes are exactly equal, but it comes close" (C1). She said that the findings challenge some theorists' position that male dominance is universal or somehow inherent in human cultures.

The value and meaning of Lepowsky's discovery was, I think, apparent to most *Times* readers. Vanatinai differs from other known cultures around the world in its apparently high degree of gender equity. Would the readers have a similarly sophisticated understanding of, let's say, the meaning and significance

of the anthropological data collected on Martha's Vineyard? Are they ready to consider that the social position of disabled people in the United States and in most other known cultures is not inevitable and immutable. It took the tools of women's studies to uncover the key ingredients of the Vanatinai culture. Similarly, disability studies is needed to investigate equitable arrangements and apply that knowledge to the construction of equitable societies. Until disability studies articulated the social and political paradigms, there was little in the way of a theoretical framework from which such research could proceed.

The title of this chapter, "Divided Society," speaks to the fissures between disabled and nondisabled people evident across time and across cultures. I contend these divides are not inevitable; indeed, if we mobilize sufficient intellectual wherewithal, I believe we can unearth other positive arrangements or, at least, envision what they might look like. In the next chapter I turn to the academy to investigate its role in marginalizing the knowledge and the people needed to reposition disabled people in the social and political arena.

Notes

1. See also Eiesland's (1994) *The Disabled God: Toward a Liberatory Theology of Disability* for an overview of religious explanations of disability.

2. For discussions of tracking and detracking, see McLaren (1994); Oakes (1985); and Polakow (1993).

3. Independent living centers are organizations run by and for disabled people, operating on the premise that, as

Joseph Shapiro (1993) writes in *No Pity*, no one "knew more about the needs of disabled people than disabled people themselves" (73). The centers provide services that allow people with disabilities to achieve maximum independence in the community and at the same time serve as advocates to change the community to make it more accessible and equitable for disabled people.