CHAPTER 4

Culture(s) and Belief Systems

Culture exerts a profound influence on the way in which people think and what they think. An individual's beliefs—whether religious, aesthetic, moral/ethical, political, or philosophical—produce his or her worldview. A worldview not only imparts meaning, it positions beliefs in relation to rituals, habits, laws, grammar, facial expressions, body image, sex and sexuality, artifacts, games, and so on. Culture is "the realm of the symbolic—that amorphous web of values, beliefs, assumptions and ideals that we internalize by being members of certain groups in a certain place at a certain time. It is within the realm we call culture that we get our bearings in life; it is there that we ingest the notions of what is good, bad, just, natural, desirable, and possible" (NACLA 1994:15). The impression of culture on beliefs and mythology, traditions and rituals, institutions and doctrines, has individual and social implications. First, culture is a milieu and medium of domination and subordination. The beliefs, ideas, and values of society at large not only reflect the dominant culture, they help to reproduce it. Second, beliefs and the attitudes they spawn are not solely determined by religious convictions or education or class or words, symbols, and expressions, or even the mass media. They are informed by the interplay of all these.

Beliefs and attitudes about disability are individually experienced but socially constituted. They are, with few exceptions, pejorative. They are paternalistic and often sadistic and hypocritical. When blatantly pejorative attitudes are not held, people with disabilities often experience a paradoxical set of "sympathetic" notions like the courageous or noble individual. Attitudes such as "I couldn't adjust to such a life, he must

be so strong" or "She has overcome so much to be successful" derive from and feed the same beliefs as pity, contempt, or shame. That is, if a person with a disability is "successful," or seems to have a good life, he or she is seen as brave and courageous or special or brilliant. Given the intrinsic abnormality or awfulness of disability, anyone living a "normal" or ordinary life must be extraordinary.

Attitudes can be paradoxical in other ways as well. In a few cultures such as the Yoruba in Nigeria and the Hubeer in Somalia disability may carry secondary deity status (even when the cause of disability is looked on as a tragedy). As the art historian Ulli Beier pointed out more than two decades ago, "The creation story of the Yorubas says that Obatala created human beings out of clay. When he had finished molding their forms, he would give them to Olorum, who would blow life into them. One day, however, Obatala went drinking. That day he created albinos, cripples, and blind people. In memory of that day, the worshippers of the Orisa [deity] are forbidden to drink palm wine; and afflicted people are considered to be especially sacred to the god and they are given positions of some importance in his shrines" (1969:12).[1]

A General Formulation of Attitudes toward Disability

The problem of disabled persons in Brazil is closely related to the history and overall situation of all Brazilian people. The paternalistic approach of the Brazilian elite has been responsible for the notion that (1) there are no prejudices against minorities and other social groups and (2) these groups are well integrated in the larger society.

Program of the Movement for the Rights of Disabled Persons (Brazil)

Periodically, relatives would come to my family's house and they would intend to ask how are you, how are you managing, but they would use a vernacular that really felt like I had just got out of intensive care, like I was dying, like I was sick.

Ranga Mupindu, executive director of the National Council of Disabled Persons of Zimbabwe

Paternalism lies at the center of the oppression of people with disabilities. Paternalism starts with the notion of superiority: We

must and can take control of these "subjects" in spite of themselves, in spite of their individual will, or culture and tradition, or their sovereignty. The savages need to be civilized (for their own good). The cripples need to be cared for (for their own good). The pagans need to be saved (for their own good). Paternalism is often subtle in that it casts the oppressor as benign, as protector. The relation between ideology and power is expressed as natural to justify relations of oppression. In *Roll, Jordan Roll,* possibly the best-known exposition of paternalism, Eugene Genovese writes,

> The Old South, black and white, created a historically unique kind of paternalist society. . . . Southern paternalism, like every other kind of paternalism, had little to do with Ole Massa's ostensible benevolence, kindness, and good cheer. It grew out of the necessity to discipline and morally justify a system of exploitation. . . . For the slaveholders, paternalism represented an attempt to overcome the fundamental contradiction in slavery: the impossibility of the slaves ever becoming the things they were supposed to be. Paternalism defined the involuntary labor of the slaves as a legitimate return to their masters for protection and direction. (1976:4–5)

Paternalism often must transform its subjects into children or people with childlike qualities. This is the most salient aspect of paternalism as it concerns disability. Paternalism is experienced as the bystander grabs the arm of a blind person and, without asking, "helps" the person across the street. This happens for wheelchair users as well. It is the experience of the waiter asking a companion of a person with a disability, "What does she want to eat?" It is the institutionalization of people against their wishes. It is the child taught only handicrafts, or the charity pleading for money to help cute crippled kids. It is these and a thousand other examples of everyday life. It is most of all, however, the assumption that people with disabilities are intrinsically inferior and unable to take responsibility for their own lives.

This kind of paternalism is also experienced by women. Henrik Ibsen captured it in *A Doll's House.* Ibsen's Nora was one of the first literary characters to challenge the paternalism of male supremacy through establishing a counterimage of the helpless, childlike woman:

> *Nora:* During eight whole years, and more—ever since the first day we met—we have never exchanged one serious word about serious things.
>
> *Helmut:* Was I always to trouble you with the cares you could not help me bear?

Nora: I am not talking about cares. I say that we have never yet set ourselves seriously to get to the bottom of anything.

Helmut: Why, my dearest Nora, what have you to do with serious things?

Nora: There you have it! You have never understood me. I have had great injustice done me, Torvald; first by father, then by you. (Quoted in Schneir 1972:182)

The myth of women as helpless or weak has always been an ideological foil for women's oppression, a paternalism, as Mary Wollstonecraft wrote a hundred years before Ibsen, that "degrade[s] one half of the human species, and render[s] women pleasing at the expense of every solid virtue" (ibid., 7). In contrast to the paternalism of slavery, which consigned responsibilities to the slaves in the form of labor, paternalism toward women and people with disabilities denies the intrinsic capacity for or interest in managing responsibilities.[2]

Paternalism, like other dominant ideologies, is built on partial experience. As Ellen Meiksins Wood and Perry Anderson have argued, no idea—no matter how ardently promoted by the dominant ideology—can take hold unless it partially reflects the real experiences of people (Wood 1986:149). This has been particularly powerful in the case of people with disabilities because until very recently they have not contested the backward ideas of the dominant culture by demanding recognition, respect, and responsibility. People with disabilities may have individually resisted the degradation of paternalism, but they have never done so collectively.

Moreover, many belief systems combine with paternalism to cast disability as physically or metaphysically tainted. This is most prominent in the least developed areas of the Third World, but it exists everywhere. Most important, people with disabilities are conceived, in the first place, as inferior and as the embodiment of bad luck, misfortune, or religious punishment. The disability itself primarily informs the conception most people have about individuals with disabilities. Their humanity is stripped away and the person is obliterated, only to be left with the condition—disability. This is why Irving Zola insisted that people with disabilities should never allow themselves to be described by a noun—"the blind," "the deaf," "the disabled." "No matter what label is used," he writes, "it cannot help but equate the person totally with his/her disability" (1984:2).

Although feminists have provided a penetrating and effective critique of paternalism, it is still a powerful ideological system. I would argue that the phenomenology of disability oppression parallels that of

women's oppression based on our similar experiences with paternalism. In the interviews I conducted, pity and shame, emotions that women have experienced, were the two most commonly identified attitudes toward disability.

Shame and pity can be considered the two sides of paternalism that are most significant in the formation of attitudes about disability. Shame looks in, pity looks upon. In *Femininity and Domination*, Sandra Bartky writes, "Shame can be characterized in a preliminary way as a species of psychic distress occasioned by a self or a state of the self apprehended as inferior, defective, or in some way diminished" (1990:85). Shame takes place in relation to others. That is, people with disabilities or their family members or friends feel shame when they themselves relate to disability in front of others, or in society. Bartky points this out by quoting Sartre: shame is "in its primary structure shame before somebody" (ibid.). Pity, like its source, paternalism, presupposes superiority. It is projected onto people. People with disabilities are primarily *subjects* of pity. The lives of people with disabilities are (considered) less, because their bodies and minds are (considered) less. To pity is to actually look at and feel bad for them. Pity is an emotion that is rooted in sight. It does not take any other factors into account. A person who cannot see or is using a wheelchair for mobility may be a happy, prosperous, well-adjusted person, but most people encountering him or her immediately feel pity.

Three Progenitors of Attitudes toward Disability

Comprehending why attitudes toward disability are universally negative requires tracing their genealogy into the many sociocultural realms that have crucial importance in socialization. In this section, I will concentrate on three of these: body/image, religion, and language. These, in their own right and in combination with other influences, predominantly inform attitudes about disability for the vast majority of the world's people.

THE BODY: WHERE SCIENCE AND IMAGE MEET

Captive. Sabotaged by my own body. I sit here seething, glaring at this pillowy snowfall, caught in a web of my dream, the taste of powerlessness it leaves behind. In Maine I was

> *fighting forces much too great for me: wind, snow, stunning cold, and of course, loneliness. It was hopeless and I knew it, but I persisted, doomed and so absorbed in the minutiae of the struggle that I forgot hopelessness. (Self-reliance, ha.) This time the enemy is me, the crumbling temple of my cancerous body, stitched together like a Raggedy Ann doll.*
>
> Protagonist in Jean Stewart's *The Body's Memory*

Historically, disability has been considered a priori a medical condition and people with disabilities, sick. This has nothing to do with disease per se but with a medical category. If people with disabilities are first a category of medicine, then by definition we are intrinsically ill, with infirm bodies and minds. People with disabilities are often set apart and identified by their "bodies" and their appearance. The fusion of science (medicalization) and body (image) is a powerful constraint.

No subject is more hotly debated by academics today than "the body." This has happened in the wake of the ascendancy of poststructuralism, especially the theories of Michel Foucault. Foucault was interested in power. As he reduced his scope of inquiry, he quickly got to the body: "Indeed I wonder whether, before one poses the question of ideology, it wouldn't be more materialist to study first the question of the body and the effects of power on it" (Foucault 1980:58). Questions about the body are immensely important to the examination of attitudes toward disability. As Rosemarie Garland Thomson writes, "Our traditional account of disability casts it as a problem located in bodies rather than a problem located in the interaction between bodies and the environment in which they are situated" (1995:16).

Cultures impart meaning through the ways in which characteristics of the body are given value or status. John Thompson, in *Ideology and Modern Culture,* termed this the "process of valorization" (1990:145). The facial scar in the Americas is considered a deformation, but for the Dahomey in Africa it is a badge of honor. Most cultures consider fat unattractive, but it is beautiful in Polynesia. Even among cultures that consider fat unattractive, some are influenced more than others by what Bartky called "the tyranny of slender" (1990:73). In many Asian cultures, for example, the body is only one of many attributes informing attractiveness. In Latin America or North America, it is the essential factor. Foucault provides an interesting—but limited—vantage point from which to appreciate the historical medicalization of disability.[3] Foucault's paradigm, which situates the body as the only verifiable "truth" or site

of oppression, contradicts the political thrust of the disability rights movement, which posits that disability is an oppressed social condition. This latter view is also advanced by the anthropologist Terence Turner in his critique of poststructuralism: "The current fetishism of the body in cultural theory must be accounted for, not as a straightforward case of consciousness-raising by history, but rather as an instance of ideological reification of precisely the kind that many leading proponents of contemporary body theory proclaim themselves, in the name of the body, to have transcended" (1995:170). The point that Turner makes so well is that the body, like culture generally, is informed by historical and social processes—most important, practical activity. The oppression of individual disabled bodies is not the basis for the oppression of people with disabilities, it is the oppression of people collectively that is the basis for the oppression of their bodies.

Recently there have been a number of important inquiries into and descriptions of embodiment and disability. These range from the disability rights activist Jean Stewart's novel *The Body's Memory* to the anthropologist Robert Murphy's historiography *The Body Silent* to Gelya Frank's ethnography "On Embodiment." Each of these treats the disabled body as central. How they treat it varies greatly. Kate, Jean Stewart's protagonist, in a series of letters and poems, evolves an awareness of her disabled body as an oppressed body. Stewart's personal experience with disability is informed by her participation in the disability rights movement. Murphy's orientation is markedly different because of his lack of involvement with the DRM. His isolation is evident in a defeatism that senses disability as a unidirectional assault on identity and a necessary dislocation or separation from family and community. Without questioning the veracity of Murphy's own experience with disability, his extension of this to a generality is unsatisfactory. On a personal level Murphy misses what is (potentially) gained from disability in terms of identity, insight, and comradeship. Gelya Frank takes an observational approach in her treatment of the disabled body. Her examination of Diane DeVries's growing self-consciousness is an important contribution to understanding how women with disabilities develop positive self-images in spite of an array of reactionary, body-centered ideas.

In the practical bodily activities of everyday life, disability presents real and often poorly understood limitations. These limitations, whether physical, sensory, or cognitive, are impulses for the production, transmission, and reception of images, meanings, rituals, and folklore in particular cultures. Popular culture has become infatuated with body

imagery. Bodies have become commodities that sell everything from beer to black bean dip. Bodies that sell are beautiful ones, and beauty is defined by how the dominant culture produces and markets images. Recently this has been at the service of sex. Many futurists contend that soon there will be little that distinguishes body beautiful from sex itself.[4]

This is an epiphenomenon of disability oppression. The future importance of body and sexual imagery, especially where they intersect, will no doubt increasingly have an impact on people with disabilities. That the selling of the body beautiful and its nexus to sex has withstood trenchant criticism from feminism should not be lost on the DRM (Galler 1984; hooks 1992; Morrison 1970; Wolf 1991). As the mass culture increasingly embraces these images as their own, people will become increasingly defined by them. The ramifications are especially bad for women with disabilities.

Rosangela Berman Bieler: "In spite of the similar discrimination disabled men and women face, there is a point where they differ: in sexuality and affection. Latin countries like Brazil have machoist aesthetic values that make a woman with a perfect body the 'ideal' type. This notion, which is exhaustively exploited by the media, generates an enormous gap between women and men, disabled or not."

The cruel treatment of women with disabilities is rooted, in many cultures, in the dehumanization of those women based in part on their dual body status—as women and as women with disabilities. Some women I interviewed reported they had been raised by their families to become good housekeepers but never to become sexually active women. Some said they never had full-size mirrors at home which permitted a view of their bodies as they grew up. One woman said as a child she frequently was lectured, "When your brothers marry, you'll live with them and help take care of their children." Moreover, everyday bodily issues such as appearance, body language, facial expressions, and posture are almost universally neglected, making these issues, especially sexuality, extremely problematic.

The implications of the present image of the disabled body—its abnormality and its ugliness—are clear. This image leads inevitably to the notion that people with disabilities are asexual. This is a powerful myth, because it is not only a product of the medicalization of disability, it is steeped in and reinforces the paternalism that consigns people with disabilities to a permanent status as children.

Maria Paula Teperino: "When I was married many people asked our maid if she could hear whether we had sex. Everyone on the street would ask me, for example, if we could have a baby. That was the first question many people thought about."

Cornelio Nuñez Ordaz: "I got married in 1978 when I was twenty-five. I met my wife on the way to the Rehab Center. First we were friends and then we got married. It was very difficult for her to be with me because her friends thought she shouldn't date a disabled man, they assumed we wouldn't or couldn't have sex, I'm not sure. During my wife's first pregnancy a lot of family and friends told us they were afraid that the child would be born with a disability."

The issue of sexuality for people with disabilities brings into relief the relationship between gender and disability mythology. Here the influences of sexuality, sexism, paternalism, and sexual repression meet, creating all sorts of ironies.

Maria Paula Teperino: "There is a cult of the body in Brazil. We call it *culto ao corpo*. You really need beautiful legs and bottoms in our culture. Machismo is very strong, and it affects the way many men think of women. Because of its prevalence, machismo leads many men to believe that a disabled woman can't satisfy him. Many even believe that disabled women cannot have children. Sons are considered necessary by Brazilians. . . . Even though my mother always encouraged me to dress well and look pretty [as I grew up], I believe she never thought I would get married. It's strange because I know she believed I would lead an intellectual and independent life, but the issue of dating and sexuality never was discussed. This was a double message and confusing, but looking back on it, I shouldn't be surprised. The myths and stereotypes about disability and sexuality based in our macho culture taught her these ideas."

Many activists believe that the men most influenced by the macho worldview have been the most condemned by it after their disability.

Federico Fleischmann: "If a man in Mexico has an accident like you, let's say at the age of forty, that's the end. I don't know one that beats this kind of problem. They stay home, and they think they are half a man. It's very difficult because of our culture in which the macho image is very strong. If you cannot play soccer any more, life has no value. Mexican culture, machismo, has a very negative effect on a man becoming disabled."

These notions extend far beyond Latin America.

Lizzie Mamvura: "In Zimbabwe, the attitudes toward disabled women are very backward. For example, in my village, but also in Bulawayo, I was told

many times that no man would want me as a woman because I had a disability. In fact, there was a strange man who always said I was his wife and this was very annoying. Finally, after a lot of effort, I built up my nerve and told him to stop this practice. He said no one would want me so he was doing me a favor. I stood up to him, and from then on I felt a lot stronger. I felt the power of talking for myself. The women's project I coordinate has this issue as a major goal. That is, to hold meetings and workshops that train leaders and others to be assertive. To speak up, to articulate our rights—the right to work, to get married, have kids. Unfortunately, we are a small minority. The biggest problem is that it's very difficult for disabled women to get married and to find a job. Even if a man is interested in marriage, his parents wouldn't allow it. They believe that having their son marry a disabled woman would bring misfortune or bad luck to the family. Also, there is widespread unemployment and Zimbabwean culture expects women to stay in their village. It is doubly bad for a disabled woman because she is shut off by people in the village and even her family."

Fadila Lagadien: "I became involved in women's issues because of sexuality issues more than discrimination. Through the disability movement, I fight for human rights because women with disabilities are told not to have children, that we are asexual, and often there is forced sterilization. In South Africa, families don't educate or support the education of disabled women because of the attitude that no man will pay a *bola* [dowry] for a disabled woman."

The similarities in Western culture should not be overlooked. In "Daughters with Disabilities," Harilyn Rousso writes, "There is a myth in our society that disabled people are asexual. . . . Because so much of female sexuality has focused on physical appearance, disabled women are particularly likely to be misperceived as asexual" (1988:140). As a practical matter, the presumption that disability is equated with asexuality has meant that people with disabilities are not socially and emotionally prepared to experience their own sexuality. Rousso again:

Parental difficulty in recognizing and affirming the social and sexual potential of disabled daughters can be understood in terms of the individual dynamics of the parents and family, and in terms of broader societal values. For mothers in particular, affirmation of sexual potential and womanhood may require the mother's ability to see herself in her daughter and to be able to identify with her. As a result of their own dynamics and history, for some mothers the daughter's disability may loom too large and make the daughter seem too disparate; the mother may then have difficulty identifying and seek to keep her distance. For example, the disability may remind the mother of her own feelings of imperfection, and she may be reluctant to acknowl-

edge that part of herself. Or, having a disabled child may seem like punishment for wrongdoing, a source of guilt safer dealt with from afar. Fathers also play an important role in the confirmation of a female child's heterosexuality. For fathers to affirm their daughter's heterosexuality, they must be able to see in their daughters the potential to become the kind of woman they could choose as a mate. Again, as a result of feelings of inadequacy, guilt, or other dynamics, the father may have difficulty seeing his daughter in this light. (Ibid., 152–153)

Disability itself is the embodiment of repulsive images of *the body,* certainly a body no one would want to have sex with. The paternalistic idea that people with disabilities are asexual contributes to the idea that they are less human, invalid or less valid. If one is innately asexual, one has something less to give and to be.

This imaged meaning of the disabled body is refined and reinforced by many ideological agents, most important, the mass media. The media's relentless production of images, in large part processed and screened through its depiction of sexuality, family life, and personal lives, is created, packaged, and marketed with assumptions about the body's importance. In response to this, a number of activist North American and European academics in the DRM have begun their own analyses and critiques. Important work has been done, for example, by Harlan Hahn (1989) and Paul Longmore (1987). Longmore, one of North America's best-known writers on disability imaging, sums up the mass media's projection of disability: "The most prevalent image in films and especially in television during the past several decades has been the maladjusted disabled person. These stories involve characters with physical or sensory, rather than mental handicaps. The plots follow a consistent pattern: The disabled central characters are bitter and self-pitying because, however long they are disabled, they have never adjusted to their handicaps, and never accepted themselves as they are" (1987:70). There are, of course, maladjusted people with disabilities who are bitter or self-pitying, but the ideological implications of these images go much deeper. They suggest that any "problem" that might develop for a person with a disability is individually based, simultaneously obliterating oppression and any socially produced barriers. Many activists from the Third World echo Longmore's assessment of the U.S. media.

Maria Paula Teperino: "Our culture is shaped so much in Brazil by the media. The media forces the picture that disabled people are not able to do certain things like have sex and be happy. An example was the polio and

virus vaccination campaigns in the past. Brazil eliminated these about ten to twelve years ago. But in the television propaganda that was used to encourage people to get the vaccine, the message always was, until about four years ago, you had better get these shots or you will get the disease, become disabled, and your life will be ruined because you will be sick for the rest of it. . . . Many of the angry characters in our soap operas use wheelchairs. When they stop being mean, they're cured of their disability. Disability, then, is in your head. A lot of the disabled on the TV soaps turn out not to have a disability, it was only in their heads. So when they are feeling better and are happy, then they become cured of their disability."

The dominant cultures in the world produce images of normality and abnormality, of beauty and ugliness, of superiority and inferiority. These images are projected by their producers to influence opinions and preferences. The sick/deformed body is stuck at the intersection where science and image meet.

GOD, BUDDHA, AND DEAD ANCESTORS

Cambodia [Kampuchea] is the worst off. It's the poorest, and their attitudes toward us are the worst. Their Buddhism says that if you lack some body function, you lack perfection, you are tainted.

Danilo Delfin, Southeast Asia regional development officer, Disabled Peoples' International

In 1993 I sat in the conference room of the largest social service agency in Thailand. In the room were leaders of all the disability groups in the country that are consumer controlled. All disabilities were well represented. The main topic was the relationship between attitudes toward disability and the barriers to social progress. After an hour or so everyone had clearly articulated the need to change attitudes that defined disability as pitiful, sad, sick, a burden, something bad. After a break I changed directions a bit and asked people to talk about their religious beliefs. Of the eleven people present, all but one were Buddhists. This was to be expected, as 97 percent of Thais are Buddhists. Many described the Buddhist notion of reincarnation. They affirmed the reason that people tried to live a good spiritual life was to avoid having a difficult existence in their next life.

I asked the ten Buddhists if they believed they had a disability because of something bad they had done in a previous life. All but one raised their hands. I then asked if they did not see a contradiction between this

belief and their collective interest in changing society's attitudes about disability. They looked at each other in dismay. The room became quiet. They realized their religious beliefs conflicted with their political and social beliefs.

This example illustrates the dilemma that disability rights activists who are religious face. They must reject a fundamental aspect of their belief or deny its conservative character. Reincarnation represents only one of the many socioreligious myths that influence the notion of disability. Others hold that disability comes from the gods or ancestral spirits or witches, from sin or lack of ancestor homage. Given different cultures, the responses to these beliefs may range from annoyance to a social sanction that isolates or even vilifies people. For example, witchcraft is a very powerful force in rural Africa and among some African-based religious sects of Latin America, especially Brazil and the Caribbean.

Joshua Malinga: "Now in Africa we have very backward ideas about disability connected to witchcraft and to life as an oppressed people historically."

Alexander Phiri: "In our culture, disability is looked at as shameful not just for the disabled person but for the family. This is connected to witchcraft, to some notions that somehow the ancestors are upset because the family is not acting in the traditional way or honoring them enough. The traditional religious churches do not even attempt to change these ideas because they are afraid of losing members."

Ranga Mupindu: "People who were superstitious believed evil spirits had cursed me."

In Africa, ancestral spirits are widely respected. Many Africans engage *sangomos* (witch-doctors) to help appease these spirits (*lidlotis* in Swazi). Sangomos exist in other places, with some similar and dissimilar roles and tasks, for example, *curanderos* and *brujos* in Mexico and *dukens* in Indonesia. Shamans, sorcerers, prophets—all play influential roles in the way their communities perceive and relate to many things, including disability. These people are often thought of as healers. Because disability is perceived as a medical condition, people with disabilities often fall within the purview of these curers. Their influence, although waning under the advance of science and Western culture, is strongest in rural areas.[5]

Religion and spirituality interact with disability in two major ways. First, religion links the origin of disability to sin, witchcraft, (black) magic, a past grievance, bad karma,[6] lack of ancestor worship, and so on.

Disability, then, is equated with something negative, even evil. Second, religion, and especially spirituality, locates progress in the realm of otherness such as heaven or nirvana, and the vehicle to it is individual purity, acceptance, prayers, alms. "In Palau, the question of what caused a disability is of primary importance—not the medical cause, but the spiritual cause. All disabilities are believed to be caused by some failure on the part of someone to follow a tradition, fulfill a responsibility, appease an ancestor" (Mallory 1992:14).

Rosangela Berman Bieler: "Brazilians look at people with disabilities as superheroes or as pitiful. Church is immensely important to these attitudes. The biggest Catholic church in the world is here. But Catholicism is declining and evangelism is growing in our country. The Catholic church fights with African religious traditions, whereas the evangelicals don't. The evangelicals stress that God will take the devil from your body, which for me means that I'll be able to walk. These people are very obnoxious. Every day, somebody will stop me and tell me I should find God and be happy. I tell them I'm already happy. They say no one can be happy in a wheelchair. I just laugh at them. While the Catholic church is backward in many ways because it promotes pity, it is not nearly as bad as these evangelicals who think the devil is inside us."

While religion hosts a panoply of reactionary ideas about disability, the institutional church may be worse. Throughout the world, the role of the church has been tied historically to colonial wealth and support of the existing social order. This has been the case with the Catholic church in concert with Spanish and Portuguese colonialism in the Americas, the northern European colonization of Africa in the guise of its messianic role to "civilize" that continent, or British hegemony and the Church of England in Asia.

One million Indians died in the mines of Peru (Galeano 1985:172, 224) and the Catholic church uttered not a word. Half a million Indonesians died at the hands of the Suharto regime in the late 1960s, and Moslems turned inward. Thousands starve each day in India, and the Hindu religion emphasizes individual contemplation. If one wants change, any kind of change, support cannot be found within the traditional religious institutions (with the exception of the marginally influential segment of the Catholic church that espouses liberation theology). They represent and reflect the status quo, both past and present. Judy Kugelmass, in her investigation of the family's adaptation to mental disability in West Java, points out the barriers to progress posed by a fusion of political and religious mythology:

A Javanese or Sudanese person will rarely answer a direct question with a direct, to the point response, out of an overriding concern for maintaining harmony. . . . Achieving harmony between conflicting and seemingly contradictory beliefs follows from a long tradition. A large part of this belief system has its origins in Indonesian religious beliefs and cosmology. . . . The "state ideology" of Pancasila, . . . the belief in authoritarian and hierarchical structures, that people should know and stay in their place, the appropriateness of behaviors as tied to social status, and the fixed nature of one's destiny stands in opposition to such [self-]development. (1989:24–25)

Many Asian cultures promote passivity. The streets of India are filled with people—with and without disabilities—who are begging. The problem is not that people are begging but the social conditions that create the need for it. Religion, the church, and the passivity they foster are part and parcel of these social conditions.

Franz Harsana Sasraningrad: "We [in Indonesia] don't like conflict. Our religion leads us to want harmony above everything else."

Rajendra Vyas: "Our religion helps us cope with our caste, our place on earth."

The relationship between religion and disability must be analyzed on two levels. First, what kind of message do various religious doctrines convey about disability? That is, do they contribute to or help break down the myths and stereotypes about disability? Second, what is the social and political role of religion as an institution? That is, does the church foster or hinder the movement for social justice? Ultimately, though there are exceptions, religion, the most influential ideological influence on attitudes and ideas, fails on both counts.

LANGUAGE AND THE POWER OF DESCRIPTION

We must take language very seriously. The feeling I have is that language is always a reflection of attitude. With the advancement of the disability movement you see a change in language.

Michael Masutha, director of socioeconomic rights, Lawyers for Human Rights, Johannesburg, South Africa

Language informs attitudes and beliefs because it is a medium of translation of expression and thought. When a word or an

idea is expressed, an image is generated. As the Russian linguist V. N. Volosinov suggests, "experience is organized" ([1930] 1973:85). When a term is used over and over again, it establishes a meaning, an image, a reality. An etymology of words about disability helps to trace the culturally based sources for many backward ideas about disability.[7] As Linda Nicholson points out, language is a social product: "Thus, many terms in our language, such as 'production,' 'mothering' and 'sex' are ambiguous between possessing a strictly limited physical meaning and possessing a more culturally loaded meaning" (1993:55). Not only is language affected by society and culture, society and culture are affected, reciprocally, by language. The kinds of images that terms like "cripple," "invalid," "retard," "confined to a wheelchair," "blind as a bat," and "deaf and dumb" generate have an ideological and therefore social and cultural impact. The words used to describe disability are loaded with social connotations. Language is regarded by many as the "most social" of all "social facts" (Schmidt 1985:53).

The meaning of disability as infirmity/deformity has a long history. This history is testimony to the force of language and its power of description. *Invalid, chirema, pena, minasvalida, ai duan*—all signify less human, innately inferior. They provide an ideological mechanism that subtly but convincingly dehumanizes people.

Ranga Mupindu: "In Africa, in our culture, we do not even use the awful term 'cripple.' It's even worse. In Shona, the word is *chirema,* which means totally useless, a failure. So a person with a disability begins life as a chirema."

In Zimbabwe, Shona and Ndebele are the two most common spoken languages. In Ndebele, the common term for a person with a disability is *isigoga,* which connotes helplessness. It means the person cannot do anything alone and must wait for assistance. In Shona, the term for a blind person is *bofu,* connoting someone without freedom. In Ndebele, the term for the blind is *isiphofu,* connoting helplessness. In Shona, the word for deafness is *matsi;* in Ndebele, *isacuthe.* Both refer to one who needs help, although the pejorative connotation is not strong in Shona. The term *ongezwayo,* meaning stubborn, is also used in Ndebele. No doubt all languages provide similar examples. Bernhard Helander writes that all the words used by the Hubeer in southern Somalia to describe particular disabilities connote illness (Ingstad and Whyte 1995:77–87).

Description of disability is not limited only to words that have a negative impact on attitudes about disability. The power of description manifests itself also through proverbs, slang and idioms, folklore, and legends. Besides the specific terms, a number of Shona and Ndebele

proverbs use disability as an idiom of culture. They are illustrative. In Shona, *chirema chinemazano chinotamba chakazendama kumadziro* translates as "a disabled person can be clever and dance if he is leaning against a wall." It means all people have abilities as long as they try and seek help. It is similar to "God helps those who help themselves." Another common adage is *seka urema wafe,* or "laugh at disability when you are dead." It means do not tempt fate. In Ndebele, *ubulima kabuhlaleli* translates as "disability does not wait for anybody." A somewhat similar saying has a more pejorative effect: *okwehlela inja lemuntwini kuyafika,* "what may happen to a dog may happen to you tomorrow." This means do not think the disabled are stupid or despise them because the same may happen to you (UNILO 1993).

For the last two decades people with disabilities have waged a political, policy, legal, academic, and philosophical struggle to make disability-related language neutral and more responsive to the changing political and cultural world. This is a difficult and protracted struggle, as Stuart Hall reminds us: "Think of how profound it has been in our world to say the word 'Black' in a new way. In order to say 'Black' in a new way, we have to fight off everything else that Black has meant . . . the entire metaphorical structure of Christian thought, for example" (1991:10). Fortunately, in some places, we can distinguish a gradual transition of terms describing disability—from "cripple" to "handicapped," "disabled" to "person with a disability." These are important symbolic steps forward.

The struggle to change language describing disability is particularly interesting in Spanish. The most common expression in Latin America is *minasvalidas,* which translates as "less valid." The term *discapitados* (less capable) is also very common. Pejorative terminology about disability abounds in Spanish, and in fact, there is not one politically correct term describing disability in the dictionary. We in the disability rights movement created our own term, *personas con deshabilidades,* or persons with disabilities. The word *deshabilidades* is not in the dictionary. When people point this out, believing that this means we cannot use the word, we proudly tell them we will not accept the language of the oppressors just because some book perpetuates the stereotypes and myths we are fighting to break down. The DRM has targeted language as an important issue for just this reason.

Maria Paula Teperino: "Lots of work needs to be done with language. People usually call us *aliejado,* which means cripple. I believe inaccessibility has a lot to do with this because people see us being carried into buildings and they think we are sick."

Narong Patibatsarakich: "In Thailand, it doesn't matter what disability people are referring to, they always say ***ai,*** which means 'to look down on.' They say ***ai duan*** to refer to amputees, ***ai bod*** for people who are blind, ***ai bah*** for the mentally ill, and so on."

Danilo Delfin: "Language of course is important. There is the history of using slang like 'cripple' or 'useless.' In Filipino the word is ***lumpo*** or ***inutil.*** We try to emphasize 'with disability'—***may kapansanan*** in Filipino; ***con pikan*** in Thai; ***chon pika*** in Kampuchean."

Everywhere in the world the issue of language appears to be illustrative of the position people with disabilities find themselves in. In China, people with disabilities have been historically called *canfei,* which means "crippled and useless." More recently, since the founding of the China Disabled Persons Federation (CDPF), the more neutral *canji,* "disabled," has appeared. The experience is similar in Asia, Africa, and Latin America since disability-related organizations have come under the control of people with disabilities. Ultimately, the language used to describe people with disabilities will change because it is now being actively contested by those it describes.

A Socialization Formula on Disability

I remember well a friend telling me when I was a teenager never to accept someone's pity because pity is the pleasure of the mediocre person.

Paulo Saturnino Figueiredo, activist,
Belo Horizonte, Brazil

People with disabilities are significantly affected by the way in which culture(s) explain the cause of their disabilities (God's will, reincarnation, witchcraft); the images disability evokes (the sick/deformed body); and how they are described (cripple, invalid, retard). These interact to produce the ways in which society at large is socialized to think about disability. Socialization works on simple symbols, simple repetition. Over and over the myth as message is repeated: disability = sickness/deformation; sickness = helpless and deformation = abomination; helpless = protection and abomination = asexuality; asexuality = childlike; childlike = helpless/protection; helpless/protection = pity; pity = disability. The message can be simplified: disability = invalid; invalid = inferior; inferior = disability. The logic is circular, but it works.

Chapter 4: Culture(s) and Belief Systems

1. For a discussion of the Hubeer, see Helander 1995:73–93.

2. Paternalism has played a crucial role in the way in which societies and cultures have constructed the category "sick role." In *The Social System,* Talcott Parsons developed typologies that attempted to simplify the social roles different social strata played. One definition of encompassed people who met the "sick role" is as follows: not responsible for their sickness; exempted from typical tasks and responsibilities; and seek professional (usually medical) help.

3. The medicalization of disability has been treated at great length elsewhere (see, e.g., Fine and Asch 1988:40 n. 1; Shapiro 1993; Longmore 1987; Oliver 1990).

4. This is the case in the futuristic, cyberpunk novels of William Gibson (e.g., *Mona Lisa Overdrive*) and movies like Kathryn Bigelow's *Strange Days.*

5. These healers have a very interesting social role and relate differently to people with different disabilities. According to Asuni, "the care and treatment of persons with mental illness by the traditional healers [in Nigeria] generally involves the active participation of relatives of the mentally ill. In fact the relatives have to live with their ill member in the compound of the traditional healers to provide creature needs of the patient and also to participate in the healing rituals. The treatment consists of administration of herbs and performance of rituals with recitation of incantations" (1990:35–36).

6. I use "karma" in the popularly understood manner as destiny, although it more accurately means only activity.

7. No matter how conservative or eclectic the doctrine, language is recognized as crucially important to ideas and behavior. Jacques Laçan gave particular attention to the study of language because he knew speech was the medium for the psychoanalysis he practiced. Saussure's groundbreaking linguistics in the early twentieth century suggested that every word is stamped with the traces of how that language had been spoken before the words had actually been uttered. Because meaning is already determined *within language,* it is extraordinarily difficult to use a word in a new way. Even the most notorious opponents of causality acknowledge the impact of language. Bronislaw Malinowski, one of anthropology's early giants, who did not believe language contained any "theory" and who divided expression and behavior, paid great attention to language. Language is for Malinowski "a conditioning stimulus of human action and . . . becomes, as it were, a grip on things outside the reach of the speaker but within that of the hearers" ([1935]1964:59).