The World

People With Disabilities in a Handicapping World

To be disabled is one thing. To be handicapped is quite another. Now that people with disabilities are coming out of the closet and proclaiming, "I am, therefore, I think," one of the things they think about is the effect of language on how they are perceived by others and how they perceive themselves. One camp abjures the term "disabled." They say it reminds them of a defunct automobile resting uselessly by the side of the road. Another camp abjures the word "handicapped." They say it reminds them of pitiful poster children looking up gratefully at benefactors dropping dimes into the can. Still another group signals thumbs down on both terms, "Inconvenience" is their word. Others favor "impaired" or "physically challenged."

Sound familiar? Just when we had gotten it straight about "Black" and "Negro," along came people who insisted on "African." It's the same battle all over again; the reasons are the same and they are good ones. Words have the power to shape images of the referenced objects and their choice is important in building or breaking down stereotypes. A group is oppressed, hidden, stripped of power, and made to feel ashamed of the nature of its being. Then social conditions shift in a way that permits the lid of oppression to be lifted a bit. A few of the stronger members climb out and hold the lid aside so that more can follow. Before you know it, you have a "movement," and one of the first orders of business is negotiating acceptable language by which to identify the members when it becomes necessary.

The World Health Organization, which developed the International Code of Impairment, Disease, and Handicap (ICIDH) used these terms to convey distinctly different meanings. Impairment referred to conditions or diseases of the body or its organs. Disability referred to any functional limitations or restrictions in the ability to carry out activity resulting from an illness, injury, or birth defect. It is defined in terms of individual functioning and, assuming there is no longer an active disease process, is relatively unchanging for a given individual. Thus, it makes sense to speak of "a person with a disability."
Handicap refers to the interference experienced by a person with a disability in a restrictive environment. It is defined in terms of social consequences so it varies greatly, depending on what the person is trying to do and what opportunities the environment offers.

To illustrate, Carol is a person with a severe disability. About 70% of her muscles are paralyzed, and that is unchanging. But she is not always handicapped. Paralyzed muscles have little to do with thinking, talking, reading, writing, and listening, which are most of what she does in her work. On a dance floor, she is definitely handicapped. In the kitchen, her handicap varies from mild, when she makes a "whatever you’ve got, throw into the pot" stew—to severe, when she tries something that requires split-second timing, like a soufflé. Thus, while disabilities remain constant, handicaps appear and disappear, in varying degrees depending on what the person is trying to do.

Handicaps don’t always come from disabilities. A big, burly college professor whose worst disability is the farsightedness that often comes with middle age commented one day that he is handicapped with respect to becoming a jockey. He mused, “That may seem a pretty trivial point, but what if I’d been born into a society where everyone else is jockey-sized and anyone who didn’t become one got put down?” People belonging to ethnic minorities are handicapped, not by disabilities, but by highly visible physical characteristics that are socially devalued. Observations such as these led to the title for the present chapter: People With Disabilities in a Handicapping World.

The new version of the World Health Organization system, the ICIDH, has maintained the general distinction between these concepts, but has moved to eliminate the labels applied to people, choosing instead to identify these categories: the body, activities, and participation.

The debate about terminology may never be fully resolved. In a syndicated newspaper column (Raspberry, 1989), Evan Kemp was quoted as observing that the terminology applied to any disadvantaged group will keep changing until the stigma applied to the group is removed and they become a truly equal part of society. In the meantime, there seems to be a general agreement within the disability community that “person first” language is most appropriate, so “a person with quadriplegia” is preferred to “a quadriplegic” and “a person with a disability” is preferred to “a disabled person.” We regard these preferences as guidelines but not as rigid rules. Collective nouns such as “the disabled” or “epileptics” are also abjured because they obscure the people and imply that disability is their most important characteristic.

Much of the handicapping that people with disabilities experience is imposed by (1) the human-made parts of the physical environment, and (2)
social customs, values, attitudes, and expectations. But not all of it is. Care
never will be able to climb a mountain and there is nothing anyone can do
about that; however, it is unnecessary for her to be stymied by flights of
stairs when ramps and elevators can serve the same purpose. Stairs are a part
of the physical world, but their continuing existence in architectural design
now that the problems they pose for a sizable segment of the population
have been recognized is a function of social values and attitudes. It is the
unnecessary handicapping effects of the human-made world that the active
branch of the applied psychology of disability is attempting to correct.

The world that disabled people must reckon with is composed, then,
two major aspects: physical objects and other people. The physical world,
by far the less complicated. Conceptually, the topic of "other people" ranges
from simple interactions between two human beings to the complex machin
ations of transnational organizations. Emotionally, it spans the cynicism of
Jean Paul Sartre's "Hell is other people" and the beauty of John Donne's
"No man is an island."

The remainder of this chapter will review environmental phenomena and
events that interact directly or indirectly with people who have disabilities
to determine their reactions and how little or how much they are handicapped
in the various areas of life performance. To begin, consider the various
external forces that impinge upon Sally, who has rheumatoid arthritis.

Getting Up and Off to Work. It takes Sally nearly two hours to get
bathed, toileted, dressed, and eat breakfast each morning. It used to take
her ten to fifteen minutes to button her blouse until she discovered a device
that reduced it to three. There may be other assistive devices that she could
profit from learning about.

Transportation. It was hard enough for her to find a job, but it turned
out to be equally difficult to find a way to get there each morning. She
usually drove, and although some accessible buses are available on main routes,
she is unable to get to the bus stop during the snowy winters. Her community
does have a dial-a-ride service, and this has been a great help. On the other
hand, it does not allow for any spontaneous flexibility in her schedule; if
she is delayed in the morning or needs to work late, she is in a bind.

The Workplace. Sally's building was made accessible when the company
put in a ramp along a side entrance. It generally suffices, although on win-
mornins she sometimes finds that the people who clear the parking lot
have dumped a pile of snow at the foot of the ramp. She has asked for an elec-
tric door opener. The company has said they will consider it, but it is too expen-
sive to install right now. The women's restroom on first floor has an access
stall, but it is located at the other side of the building from her office.
Disability Experience

It is not all of it. Carol would say anything anyone can do is the same as being stymied by flights of stairs. Stairs are a part of the world that the architects and engineers are attempting to correct. The physical world is not composed, then, of "people." The physical world is of "other people" ranging from the complex machines it spans to the cynicism of the beauty of John Donnell.

One more mental phenomena and one more who have disabilities show they are handicapped. She is to consider the various ramifications of arthritis.

Two hours to get up and go. It used to take her two hours to get up after a night on main routes, she discovered a device that she could push, she slept in, she discovered a device that she could push on in her schedule; if she didn't she was in a bind.

The company when the company closed, although on winter days, the parking lot has been asked for an electric car, but it is too expensive for the building. She has been told there would be little to expect. Enough progress has been made realistic to try, and the Catch 22s are the barriers to leaving their groceries unattended while they fetched

...allowed to use the spacious restroom adjoining the executive's office, and she always felt so foolish going in there.

The Job Site. This was a miracle, which is why she put up with all there were. Her counselor got a rehabilitation engineer to design a special desk for her. She could reach what she needed to operate independently. In the meantime, waiting for her ride, she set everything up for the next day. She got someone to help her.

The Transportation. A big day arrived. Sally was invited to attend an educational meeting that could have an impact on her chances for promotion. She arranged for a ride to the airport, and made it through check-in uneventful. The airline insisted on putting her wheelchair into the baggage compartment of the plane, however, and when she was reunited with it after the plane had been damaged and required repair before it could be used.

When Sally has a friend who drives her and helps her with her shopping on Saturday. Imagine her surprise when she found a new barrier, designed for the theft of shopping carts at the supermarket, which also kept her from entering. The barriers were removed after a few weeks. She is not sure this was because of the complaint she filed or because non-disabled were objected to leaving their groceries unattended while they fetched

The Education. Sally used to ice skate before her arthritis became too severe, and she loved the follies. She never used to go because of the accessibility problem. As soon as the auditorium announced their "renovations for the disabled," she got a group of friends interested in going with her. They sat in the regular seating area. She sat alone in the area reserved for who use wheelchairs.

The Attendant. She finally got an opportunity for advancement with another which required her to move. She went into debt the first three months, but she got an attendant to help her move until she could locate an accessible apartment in which she could live independently. She applied to a number of complexes that had advertised as having apartments available, but when she arrived, she was told they had already been rented. She doubted that it was coincidental that she arrived just "hours too late" on so many occasions. Her experiences could be depressingly to even read about unless note is taken that such frustrating Catch 22s are signs of progress. A few years ago she might not have bothered to leave the house at all because she’d known there would be little to expect. Enough progress has been made realistic to try, and the Catch 22s are transitional phenomena that will disappear in time.

Sally was confronted by a series of barriers to living independently, working, and enjoying leisure time. Some of the barriers were physical, such as
the stairs and inaccessible restrooms. Others were attitudinal, such as the airline policy that assumed disabled travelers don't know their own needs. Happily, her experiences included helps as well as hindrances: employers who were willing to hire her, friends who cared and would offer assistance, even the auditorium that accommodated her physical, if not her social, needs.

At the other end of the spectrum is the example of Juanita, who had worked for 20 years as an office manager for a physician who became her greatest friend and supporter. Two days before she died, Juanita, 56, put in a full day at the office. In recent years, when she was no longer able to sit in a chair, she worked from a special bed that had been installed in the office. She used a number of assistive devices to run the office efficiently. The doctor even provided a van that was specially adapted to transport Juanita and her equipment.

How people react and adjust to disability is partly determined by the mix of helps and hindrances they encounter in their lives. As pointed out in the previous chapter, environmental determiners of reaction to disability can be divided into two major types: those that are palpably present in the person's immediate environment and those that are interwoven more subtly into the larger cultural context. The former may vary sharply from one individual to another; the latter tend to be uniform for all individuals in a given time, culture, or subculture. In this chapter, environmental influences have been divided in still another way: those relating to the physical world and those relating to other people.

These distinctions are useful for comprehending the totality of interacting external influences that shape behavior; but, true to life, they do not remain in neat categories when in operation. The physical stairs cannot be separated from the architect who designed them, and the architect cannot be separated from years upon years of tradition in design.

With this disclaimer regarding the precision of categorization in mind, the ensuing pages will discuss first the environmental influences seen mainly as cultural determiners and therefore as exerting similar influence on all people with disabilities in a given time and place. Second, we will explore influences that are tied to individuals' personal situations and therefore reflect marked variations from one person to another.

The Societal Context

It may go without saying that the cultural context referred to in this volume is the United States of America at the beginning of the twenty-first century.
Experience

A few cross-cultural comparisons will be drawn, but, unless otherwise specified, the previous assumption can be made. The fact is, some of the most powerful influences on reactions and adjustment to disability may be pannatural, suggesting that they are, *au fond*, rooted in human nature. A large portion of the introductory chapter was devoted to what is considered the most potent negative influence of all: devaluation. There it was admitted that the genesis of devaluation, whether biological or culturally learned, is unknown. Being unable to discern which determiners are immutable aspects of human nature and which are potentially alterable products of human culture, all are arbitrarily assigned here to the "societal context."

A few isolated instances in which disabilities (or disabled individuals) have been revered rather than devalued can be cited. The best known example is epilepsy, regarded in earlier times as "the sacred disease." This elevated status was probably a result of the fact that epilepsy was very common among the ruling classes, and these rulers had little tolerance for being the brunt of devaluative statements. In addition, a few individuals scattered throughout history have been regarded as almost holy for reasons directly related to their disabilities. A current example is an artist from Japan who has mental retardation; his works are revered not only because of their superb quality but also because of the childlike innocent who produces them.

Exceptions aside, the rule is devaluation, and its form and degree are heavily influenced by the surrounding culture. Devaluation can be blatant or it can be subtle. The Nazis, to give a clear example of blatancy, killed disabled people. Other societies, for the greatest part, have been so subtle that their devaluative practices went unrecognized as such for generations, until the new breed of activists started pointing them out. In the United States, during the 19th and 20th centuries, laws provided for the involuntary sterilization of individuals with cognitive disabilities (Pfeiffer, 1999). Some people, including those with epilepsy, were prevented from marrying, and children were sometimes taken from parents with disabilities. The creation of separate, segregated educational and work systems provide prime examples in both the Eastern and Western hemispheres.

Devaluation may be tough, or it may be tender. Treating disabled people as pariahs and forcing them to sit outside the city gates to beg was a very tough stance to take. This attitude followed from a belief that "the afflicted" were sinners in the eyes of God and deserved to be punished. A more tender approach is to consider people with disabilities as unfortunates, not outcasts, and worthy of pity rather than contempt. Blatant or subtle, tough or tender, devaluation is devaluation and this is well understood by the objects of either attitude. Such awareness is illustrated by the comments of a woman with a
severe disability who had just been introduced as a keynote speaker. Invited to speak because she has clearly made a success of her life, she acknowledged her introduction by saying, "I guess I will never stop being surprised to hear myself referred to as 'someone less fortunate than the rest of us.'"

Not only the form but the degree of devaluation is shaped by the prevailing philosophy of the culture. A dominant element of the Nazi philosophy was the principle of Aryan superiority, which leaves no room for damaged specimens, especially among Aryans. On the other hand, the principle of reincarnation, which is embraced by many cultures, allows for no misfortunes. An important element of the latter is that one chooses one's body, one's parents, one's total life situation for the purpose of "working out karma." Thus, one chooses to live in a disabled condition for reasons related to spiritual development; one is not the victim of a regrettable accident. A rehabilitation administrator who has come to embrace the principle of reincarnation commented one day that, as one result, when she meets a person who is mentally retarded she no longer feels the pangs of pity she once did. She doesn't think of herself as more fortunate than (and therefore superior to) an unfortunate (and therefore inferior) person. She relates as a peer, a colleague spirit, and finds herself asking, albeit quietly to herself, "Ho there... what are you working out this time? I wonder if you are at a higher level of development than I for having come to such a test."

**Attitudinal Barriers**

This widely used term says, in essence, that disabled people tend to be rejected by other people. The most forceful rejecters used to be other disabled people who didn't want to "identify," but the movement has changed that. Perhaps the commonest attitudinal barrier is the tendency to overgeneralize about what "they" are like, whether "they" can be helped, whether "they" can communicate directly with salesclerks or need nondisabled intermediaries, whether damaged bodies can coexist with undamaged minds and the reverse. Only rarely are attitudinal barriers manifested openly and directly, such as in expressions of distaste or avoidance of eye contact, conversation, touching, or even proximity. They are more apt to be manifested indirectly, in the form of exclusionary practices deemed "necessary" for the safety or convenience of people in general. The term "attitudinal barriers" combines, in a sense, the effects of devaluative attitudes and discriminatory behavior.

In order to understand why attitudinal barriers exist, it is necessary to consider what qualities are venerated by a culture and are found lacking in
certain groups. Some of the issues selected for review appear to be specific to our culture; others are so pervasive across geography and history as to suggest that they emanate from human nature itself.

Overvaluation of Rational Intellect. Since the seventeenth-century beginnings of the age of reason, Western society has placed an increasingly high premium on the particular type of intellect referred to as logicodeductive, sequential, rational, or linear-thinking. Another type, which earlier in history was greatly prized, concomitantly came to be ignored or even derogated. “Women’s intuition” was for long nearly the only reference made to the inductive, simultaneous, intuitive, or nonlinear thinking mode that was once considered the path to truth. It seemingly did not serve well in the growing physical sciences (and their mathematization) and, over the course of three centuries, was declared illegitimate and practically forgotten.

Partly as a function of societal dismay over where science and technology have led, and partly as a function of their very progress in the field of brain research, intuition is in the process of being rellegitimized. Some researcher-theorists believe the two types of intellect can be assigned to the left (linear reasoning) and right (nonlinear thinking) hemispheres of the brain. As a direct result, intuition is gaining scientific respectability. As an indirect result, we are beginning to recognize that certain people, those intuitive souls who are lacking in logicodeductive reasoning ability, have been unnecessarily handicapped with respect to mental functioning simply because their kind of gift was disdained.

People labeled “mentally retarded” are sometimes gifted in terms of nonlinear, instantaneous data processing ability, and Mike appears to be one such person. His ability to penetrate immediately the obfuscations that generate and escalate misunderstandings between people is the talent that allows him to mediate others’ arguments effectively. He does not reason through the haze in stepwise fashion: he appears to intuit at once what has gone wrong. His gift has become recognized in the light of recent attention to this other type of intellect, but it is important to note that it is rewarded only as an interesting oddity. This society as yet offers only the rarest opportunities for acknowledgment equivalent to that given sequential reasoning; specifically, there are few jobs that explicitly draw on such talents and pay living wages to individuals so gifted.

Overvaluation of Physique. Physical beauty and prowess are not only very highly prized in society, most cultures also set stereotyped, narrow bands of standards as to what “makes the grade.” Here, today, men should be tall, tanned, and muscular, with copious character in their rugged faces. Women should have gigantic breasts but no fat anywhere else and a minimum of
character lines to mar delicate, regular, facial features. Ideally, both shall appear youthful regardless of their chronological age, but for women it is a must. Athletic prowess is a must for men and highly desirable for women if not taken to extremes. Women have more latitude here; if she can't hit a decent game of tennis, a woman is okay if she can dance or has the look of a "hard body." Such values are so deeply inculcated that merely to associate a product with youthful movement and beauty is to elevate its sales. We want "the image" for ourselves. Most of us feel, in varying degrees, that we must at least approach it in order to be happy. But some of us don't. As Kip pointed out, people with disabilities are almost automatically disqualified.

The counterculture of the sixties was a helpful ally in combatting the barrier in that it rejected the traditional standards and attempted to widen the range of acceptable physical attributes by (social) force. But according to well-publicized recent research, there is still a strong correlation between physical attractiveness and such hard-to-define but universally desired emotions as success, happiness, and life satisfaction. It doesn't help to label them shallow, irrelevant, inhumane, and undemocratic. It is a force to be reckoned with, and some ways for doing that will be discussed in Chapter 11.

Undervaluation of Spirituality. Just as modern society appears to have overstressed the importance of rational intellect and physique at the same time it has reduced emphasis on matters of spirituality. These are the outgrowths of the age of reason, with its advancing science, technological preeminence, materialism. Descartes gave us the concept of mind-body dualism in the seventeenth century, and we have been using and misusing it since. Somewhere along the line, the spiritual aspect of our being was mislabeled. Like intuition, it is in the process of being rediscovered, and for essentially the same reasons. Again, a segment of the counterculture contributed substantially to initiating the shift.

People with disabilities are handicapped differently by a materially oriented society than by a spiritually oriented one. A society which combines technological advantages of the West with the spiritual values of the East might not handicap its disabled members so much. When you conceive of yourself as nothing more than mind and body, and one or both of these have been damaged irreparably, it doesn't leave you very much that is still intact. The balance changes, however, when credence is given to the "soul" which seems to be impervious to the onsloughts of disablement.

The degree to which a culture is materialistically oriented influences its reactions to individuals with disabilities in a number of practical ways. Along with technological advancement, the levels of industrialized affluence rise, yielding many benefits. Concomitantly, the ethic encomp...
by the phrase, “I am my brother’s keeper” diminishes, to be replaced by a
welfare system. When responsibilities formerly carried by the family and the
church are shifted to the state, a businesslike atmosphere, rather than a loving
climate, is created for recipients of care. This has both good news and bad
news aspects. These and other cultural influences relating to style and level
of social and technological development will be examined next.

Blaming the Victim. It is very difficult for humans to acknowledge how
utterly capricious fate can be. Such an admission carries with it a disturbing
awareness that we are not always in control of our own destinies. “If the
fickle finger could point at them, it could someday point at me.” To protect
ourselves from the sense of impending vulnerability, we work things around
in our minds to make misfortune the victim’s own fault. “He must have
brought it on himself. I’m not bringing anything like that on myself; therefore,
I needn’t worry, it won’t happen to me.”

A very popular form of blaming the victim is the attribution of masochism
to people who are victimized by serial misfortune. We don’t like to believe
that fate could really be so unfair. We search for other explanations and find
one that is sanctified by modern psychology: the urge toward self-destruction.
However unexplainable that might be, it is preferable to giving up what Jules
Masserman (1955) has called an essential, human delusion of invulnerability.

Like devaluation, the method of blaming the victim is sometimes blatant,
sometimes subtle, sometimes tough, and sometimes tender. “I’m not surprised,
she’s always been accident prone!” “Arthritis occurs with people who are
filled up with pent-up hostility.” “He deserves it for trying to rob that store
in the first place!” “Poor thing, if she’d just been able to think a little faster,
the accident could have been avoided.”

Unfortunately, after thus reassuring ourselves, we start looking askance
at the “unfortunates.” Nowhere is this seen so clearly as with disabled people
who develop one complication after another or additional, unrelated disorders.
Family, friends, and rehabilitation workers alike find themselves saying, “It
can’t just be happening; she (or he) must be doing something to cause all of
this.” Whether he or she is or isn’t, fate is thereby dealing one more blow
for him or her to react to.

Insistence on Mourning. We humans also have a tendency to assume that
anyone who has lost something that we hold dear must be mourning its loss,
be it physical prowess, money, power, or anything else. Allowing for the
possibility of easy relinquishment seems to suggest that what we possess is
unimportant. Au fond, it may be less what we possess than what we strive
for that stimulates this insistence on mourning. When we dedicate our energies
and consciousness to amassing wealth or building the body beautiful or
gaining influence and power, we may not want to hear that someone else has discovered—in one way or another—that goals of these sort are not, after all, essential to happiness. What is the meaning of our struggles, then? To preserve the meaning we have ascribed to our own lives and efforts, we thus make the assumption of “sensible mourning.” It is viewed as only sensible that a person would mourn, perhaps unremittingly, the loss of an essential ingredient of a satisfactory life.

This simply isn’t always a valid assumption. Earl, for example, found that he mourned the loss of his disability, a process no one else could understand more than he had mourned the loss of his vision. Stephen’s disability also brought a compensatory trade-off in relieving him of the pain of failing in his father’s eyes. That mitigated his mourning substantially. Even Dana, who mourned more expectantly for a number of years, eventually surpassed mere reconciliation in an avowed embrace of all of her life experiences including disability. Dickards may insist that this is “sweet lemon rationalization,” but it does not seem sensible to believe that someone who has experienced disability knows more about how it feels than someone who has.

**Technological Level**

In recent years, the United States Government has made a concerted effort to take mainland rehabilitation know-how to the islands in the Pacific. As a result, a number of rehabilitation experts have experienced directly the dramatic impact of cultural development on the lives of people with disabilities. Taking a spinal cord injury as an example, in Micronesia the concerns include getting the person into a canoe to reach a ship that can take him or her to a hospital in Hawaii, preventing pressure sores when he or she sleeps on a grass mat on a dirt floor, and finding a wheelchair that can withstand more than six months of the high humidity and rough terrain. One expert observed that mainland values do not mesh well with life in Micronesia. She commented:

> The only real work there is gathering copra, which physically disabled people obviously can’t do. But in order to be eligible for vocational rehabilitation funds to get the needed medical care, they are “punished” by being forced to go to work doing something... something that has no meaning in their frames of reference.

To those of us imbued with modern technological and materialistic standards, it would seem clearly preferable to be disabled in a culture with technological means to circumvent many of the functional problems dis
generates. Having grown used to the convenience and independence offered by motorized wheelchairs, powered lifts, electronic magnifiers, talking calculators, and portable computers, it would be hard to go back to a lifestyle bereft of these spin-offs from the aerospace industry. A story about motorized wheelchairs provides a striking example of how the application of technology can influence not only the ways individuals feel about having disabilities, but their efforts to adjust and build satisfying lives as well.

Years ago a number of rehabilitation hospitals had policies discouraging the use of motorized wheelchairs. It was reasoned that people with weak upper extremities would profit from the exercise of wheeling manual chairs. Lost in this trend were those with so much upper-extremity weakness that they could not propel manual chairs at all. Rather suddenly, a change in philosophy came about, and the “personality changes” observed in many affected individuals were remarkable. Several years later, Bob related how his new wheelchair affected him.

I got polio when I was too young to remember. As long as I have known me, I’ve been almost totally paralyzed. I’d spent all my life at [hospital] until a couple of years ago. They didn’t know what else to do with me. I went all the way through high school there, and everyone used to tell me, “You’re so bright, you should go on to college,” but I just couldn’t imagine it. After I finished school, I just sat in the hallway all day and talked with whoever came by.

When they first asked me if I’d like to have an electric wheelchair, I said, “No.” It seemed freaky, somehow, and I was afraid I might lose control of it. But they kept after me and boy, what a change in my life! All of a sudden, for the first time, I could go wherever I wanted to whenever I wanted to... I didn’t have to wait for a “gray lady” or escort service to push me. I went all over the hospital, down the street to where some shops were, and I finally enrolled in college. Somehow, being able to move around on my own, I could imagine doing it. I’ve done really well in school and just moved out into my own apartment.

It also turned out that the no-motorized-wheelchairs policy had been a disservice to people who could wheel their chairs, but with enormous energy expenditure. The hospital staff member cited earlier went through the same philosophical transition and relates that, after adopting the use of a motorized chair, she greatly increased her artistic and domestic activities because she at last had the energy to pursue them. A policy designed to maximize independence had proved to have the opposite effect.

The shadows of the anti-motorized-wheelchair bias still crop up in the attitudes of some individuals with spinal cord injuries who have developed carpal tunnel syndrome and shoulder pain after years of making their upper extremities function in place of their legs. Many still resist the shift to power
equipment, however, because they fear that it will make them appear to be "more disabled."

Even more centrally influential on the quality of life for disabled people is the degree of industrialization and affluence that technological development permits. For example, new kinds of jobs are created, as technology advances, that do not require workers to move or manipulate physical objects—"thing jobs," in the terminology of *The Dictionary of Occupational Titles* (U.S. Department of Labor, 1991). "People (service) jobs" and "data jobs" come into being, jobs that workers unable to use their bodies as primary work resources are able to do. Moreover, an affluent culture can better afford to absorb the costs engendered by people with disabilities, restoring their functioning or supporting their additional needs when restoration is not possible.

Another benefit stemming from the proliferation of technology is that accommodations are now available that bring many vocational choices into the realm of possibility that otherwise might not have seemed feasible. For example, prior to the availability of personal computers, optical scanners, and the like, a blind person would have been ruled out of a job like accounting that required constant handling of papers and data.

On the problematical side, as the tempo of technological development increases, the rate at which jobs obsolesce is stepped up accordingly. This creates retraining needs among workers with or without disabilities, but narrowed options make such transitions more difficult for the latter.

*Socioeconomic and Political Style*

Relatively independent of their level of technological development, societies may diverge or change over time, in political philosophy and in socioeconomic style. The extent to which a society chooses to direct some of its resources toward the betterment of life for individuals with disabilities by creating enriching a welfare system, passing protective legislation, and channeling monies into service programs has a powerful impact on what it means to experience disability.

As an example, only a little over two decades ago, United States citizens so severely disabled as to require the help of a personal care assistant had only two options: to be cared for by family or friends, or to live in a maintenance-care institution. The alternative of being provided with funds to live as an independent adult did not exist. Today, independent living has become the norm as a result of legislation creating a system that takes account...
of both human and monetary needs. (Some of the ways in which this same system breaks down, from the functional and psychological viewpoints, will be examined in Chapter 3.)

All of these cultural influences on reaction and adjustment to disablement are relatively uniform for people who experience disability within the same society during a particular period of time. The following section will take these as givens and explore other environmental determiners that are more variable from one individual's situation to another's.

**Cultural Influences**

The preceding discussion addresses issues that apply, in general, to contemporary American society. At the same time, awareness has grown that this is a multicultural society, composed of varied racial and ethnic groups with diverse perspectives on life and disability. Recognition should also be given, then, to ethnic and cultural influences that are narrower than national characteristics and broader than a person's immediate environment. Swartz-Kulstad and Martin (1999) have likened society to a stew, in which people retain their distinct cultural heritage and are also flavored by the environment around them. Cultural forces help to shape an individual's values, interests, aspirations, communication patterns, and behaviors. They guide an individual in understanding the meaning of events, including the onset of disability, and help to prescribe how the individual and family should respond.

For the most part, the American rehabilitation system grew out of the paradigm of the dominant Euro-American culture, reflecting the values of individualism, independence, and the importance of gainful employment. In medical rehabilitation, great emphasis is placed upon functional independence in activities of daily living, and families are discouraged from doing things for a person that he or she might learn to do alone. For some cultural groups, standing by and watching a father or mother struggle to dress or eat without help is tantamount to extreme disrespect. Within the vocational rehabilitation arena, cultural differences may be reflected in such things as orientation to time and willingness to move from one's traditional residence in order to obtain training or work. Such conflicts could certainly impair the effectiveness of the rehabilitation system's work with an individual, thereby influencing his or her response to disability.

Swartz-Kulstad and Martin (1999) searched and analyzed more than 400 publications related to culture. Their qualitative analysis revealed five primary domains of culture and context, each with a number of subcategories. The
findings suggest the many ways that culture affects individual perspectives. The first domain, ethnocultural orientation, reflects the extent to which one is involved in the culture of origin and in the dominant culture. Other elements in this domain include beliefs, values, norms, coping style, cognitive style, and traditions or ceremonies of the cultural group. Family environment, the second domain, involves both family relations and structure. The third domain, community environment, encompasses the community structure and support networks as well as norms and migration. The last two domains are communication style and language. Language facilitates the exchange of information between people, partly through the use of mutually understood words and partly through all of the nonverbal expression that occurs between them. Clearly, the potential for miscommunication is rife between a culturally naïve counselor and an individual from a different background.

Early efforts to remove the cultural blindfolds from rehabilitation practitioners often took a cookbook approach. Papers described the “typical” beliefs and behaviors of African Americans, Native Americans, Asian Americans, Latinos, and other groups. Perhaps it is useful to know that individuals of Asian heritage may be reluctant to describe their problems to strangers and may rely strongly on guidance from family elders. At the same time, such generalizations overlook great differences that may exist within any given ethnic group and perpetuate inaccurate stereotypes. An obvious problem involves lumping such diverse and huge cultures as Chinese, Korean, Japanese, Indian, Indonesian, Samoan, etc., into the category, “Asian.” Even within one of these groups, significant disparities may reflect differences in socioeconomic status, degree of acculturation, and many other factors.

So how is it possible to acknowledge the influence that culture may have upon response to disability without falling into such traps? Some writers (Marshall, Johnson, & Johnson, 1996) have advocated developing a transcultural world view, one that welcomes and appreciates different perspectives as equally valuable, and that is open to varied solutions to issues. Rather than seeing the world in terms of dichotomies or fixed categories, counselors need to accept the existence of multiple realities and strive to understand the perspective that each individual brings. Coming back to our discussion of factors that affect an individual’s response to disability, perhaps the most appropriate comment is that heritage plays a significant role in creating the filters through which a person views life experiences and that heritage must be explored if the individual is to be understood.

The Immediate Environment

A counselor specializing in the problems of people with very severe physical disabilities summed up his years of experience by expressing the opinion that:
The main problem with being disabled is being poor. If you were rich enough, you could buy all the fancy gadgets available to do what they can, and whatever was left, you could pay other people to do. I don't think being disabled would be so bad if I had a valet, a chauffeur, a personal secretary, a big, accessible home, a van with everything, and no worries about grubbing for a job.

This counselor has not experienced disability, and some of those who have may feel he is missing some important points, but he also is making one: how rich or how poor you are has considerable impact on how miserable disability can make you. Moreover, one of the problems with disability is that it tends to make or keep you poor. Available income may not be the problem associated with disability, but it is surely an important determiner of reactions and adjustment to it.

**Family Influences**

Income is but one aspect of the familial milieu surrounding a person with a disability. Other relevant variables relating to family structure and dynamics include the family's social standing and power base in the community, parental acceptance, spousal loyalty, and the proffering of practical and/or moral support. Having a family member who is skillful and assertive in mastering crisis, a name that is recognized by local agency personnel, or a relative who plays golf with the major employers in the community can alter materially the negative ramifications of most any disability. The effects of these and many other aspects of family capability and interaction will be examined in detail in Chapter 4.

**The Influence of the Community**

Just as one's position within the community makes a difference in the consequences of a disability, numerous aspects of the community itself influence the disability experience. Perhaps most basic are the community's size and location. A small town may offer a quality of human support that is lost in the big city, yet lack the sophisticated paraphernalia and services the latter provides. The differing demands made upon rehabilitation systems by rural and urban communities are felt most keenly by those in rural areas, since most service models are designed in and for the denser population centers with their relative wealth of medical, educational, psychosocial/vocational, and other resources.
The extent to which a given community has responded to protective legislation by eliminating mobility barriers, providing full inclusion for disabled youngsters in the public schools, and other such actions, also will have significant impact. So will the existence of voluntary service organizations and the service orientation of local churches. Does the transit authority have buses with lifts or at least a demand-response option for those unable to board standard buses? Does the responsible department of local government energetically enforce existing protective legislation? Is there someone with a significant disability among the ranks of elected officials? How far away is the nearest active center for independent living? The answers to all of these questions portend much concerning the quality of life for individuals with disabilities in a given community. These are the problem areas being attacked by the activists determined to alter the stimulus conditions "out there," all of which they view as stemming fundamentally from the attitudes and actions of "other people."

**Institutionalization**

Most people with disabilities have occasion to experience that unique kind of community known as "an institution." This may be limited to hospital stay during the acute treatment; or it may include additional time in a hospital for rehabilitation. For some, an institution becomes home for a major part of their lives.

However, utopian an institutional setting might be, the inhabitants are there by choice. Ordinarily, institutionalization is grudgingly accepted as unavoidable necessity for accomplishing some other goal, such as rehabilitation. In point of fact, few, if any, institutions are utopian; by their very nature they tend to restrict the degree of freedom and violate the privacy of the people who dwell in them. Depending on specific institutional policies, procedures, and personnel, these effects may be minimized or magnified.

Erving Goffman (1961), in his well-known work *Asylums*, describes he calls the "mortification process" wherein institutional residents are deprived not only of their privacy but of their power over themselves, or for the convenience and efficiency of those running the institution. Rules would be considered intolerable if imposed on noninstitutionalized citizens, enforced and accepted. That they are behaviorally accepted does not in an absence of psychologically damaging consequences. Yielding self-control, even for a time, may have long-lasting, negative effects. Staff in rehabilitation hospitals have become alerted to the irony that the patients most...
cooperate with medical usurpation of crucial decision making about their lives during institutionalization may be the least well prepared to resume effective, assertive self-mastery when they return to the ordinary world.

Psychologically speaking, it may be the irony of all ironies that, in hospitals, the staff member most important to the patient is the one considered least important, if prestige, remuneration, and care in selection are any indicators. A long-term follow-up study (Kemp & Vash, 1971) reported that the vast majority of a sample of fifty spinal-cord injured individuals interviewed five to ten years after hospitalization, when asked to recall their “brightest memories associated with being in hospital,” responded with recollections concerning particularly caring members of the nursing assistant staff. Obversely, their “grimmem recollections,” in the main, concerned assistants who were cruel or demeaning. The more prestigious and highly paid staff were not once mentioned. It is the assistants who carry out the most intimate ministrations; it is they who are there at the end of the day when memories and doubts flood consciousness, and on the weekends when no visitors have appeared. Yet in many settings, these employees are still selected and paid in the same way as the housekeeping staff who take care of the physical plant.

Roberts’ observations on the indignities to which he was subjected during mealtimes in an institution (see Chapter 1) suggest that some of the caregivers he experienced might have been better suited to building maintenance tasks. Using feeding as a potent example of the emotionally loaded interactions between attendants and patients, it is important to note that not all of the error results from uncaring or hostility-laden practices. Baby talk accompanying the feeding of an adult patient can have equally destructive effects. (Whether infantilization of this sort is also a form of hostility belongs to another book.)

Agencies

Contact with institutions doesn’t end when one is no longer a resident of one. After returning to the community, people with disabilities often continue to interact with other types of “bureaucracies” or “agencies.” These provide vitally important services and are appreciated for that reason, but the mortification process goes on. In order to receive the benefits allowing survival outside of a residential institution, disabled people still must tell all, hand over the reins, and oftentimes swallow much, possibly for a very long time. The widely publicized suicide of Lynn Thompson in 1978 galvanized the disabled community into a coalition determined to alter the laws and agency procedures that resulted in her conclusion that death would be preferable to the life she
foresaw upon being forced to return to a residential institution. Chapter 3
will treat these and related subjects in more detail, and Part II will take the
further step of exploring ways in which problems cited can be minimized.

Regional Differences

Just as legislative thrusts and government funding trends affect disabled
people in relatively uniform ways, so may similar phenomena influence
subgroups of people, as defined by their localities or in various other ways.
Marked regional differences have been noted in the nature and effectiveness
of national programs from one state or locality to another, but disabled people
seldom have the choice to live where the services are best. One effort may
be reflected in the tendency for motor-disabled people to migrate to California.
This is not solely a result of more extensive health-related services, however;
the Mediterranean climate and relatively accessible architectural style offer
sufficient lure. The happenstances of geography, climate, and building style
can have a significant impact on how one reacts to a disability. For example,
having to cope with snow when you’re blind or use crutches can take its toll
on your safety, your independence, and your sense of humor.

As always, it is not just the physical facts that create or eliminate problems,
but also how people respond to them. In the western states, for example, if
your home doesn’t “work” for you after you begin using a wheelchair, the
chances are you simply will move into one that does. This is not so in New
England and other parts of the eastern seaboard. The tradition of the family
home is far more sacrosanct there than in the West, and a home that has
served a family for several generations will not be relinquished lightly,
however difficult it may be to get a wheelchair in and out, or up and down
the stairs.

Exotica

One influence that affected a particular subgroup of disabled people positively
for a number of years is worthy of mention because of its implications for
future reform vis-à-vis environmental influences in adjusting to disability.
This was the operating style of the National Foundation for Infantile Paralysis.
The families of children (or adults) who contracted poliomyelitis were given
the financial help they needed to deal with catastrophic illness, but they were
not subjected to the mortification process that accompanies such government-
administered aid as Supplemental Security Income. The program was "abused" in a way that consternated almost no one: because only polio patients were eligible, some physicians are thought to have intentionally misdiagnosed cases of Guillain-Barre or infectious neuronitis, which have very similar symptoms. It saddened rehabilitation workers to see patients with still other disabilities have nowhere to go for comparable help. Today, the generations of "polio kids" who are now adults can appreciate the Foundation that helped without imposing elaborate screening/monitoring systems that shatter the peace of mind financial aid should bring, by destroying dignity and privacy during a time of extreme emotional vulnerability.