

# DISABILITY

*and Public Health*

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# CHAPTER 5

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## CULTURE AND DISABILITIES

*Germán R. Núñez G., Ph.D.*

### Introduction to Culture and Disability

CULTURE HAS BEEN DEFINED as the patterned behaviors and mental constructs that individuals learn, are taught, and share within the context of the group to which they belong (Whitten and Hunter 1990). To an anthropologist, the term “culture” refers to the way of thinking and behaving of a particular population or society (Ember and Ember 1990). Cultural influences operate largely at an unconscious level—like an unwritten dictionary that provides the meaning and definition of events to its members such as how to process, evaluate, and interpret the world (Landrine 1992). The truth is that there are many definitions of culture and while some are behavioral in emphasis, others—just as valid—emphasize the symbolic aspects of life that make it possible for individuals to rationalize and make sense of the life they live. The challenge for cultural theorists is to formulate a definition that combines all of these aspects (Schweder, Jensen, and Goldstein 1995). Hall (1976) recognizes the multiple uses and meanings ascribed to the word “culture” when he describes culture as “a word that has so many meanings that one more can do it no harm.” Most authors, however, agree that culture refers to a set of values that are common to a group of people, and that these values are continuously taught, both consciously and unconsciously, by members of the group to new members, thus passing the culture from one generation to the next.

The purpose of this chapter is to review the concept of disability through a cultural lens. Public health is fundamentally committed to issues of cultural competence. The essential services of public health include understanding and resolving community health problems, as well as ensuring a competent public health workforce (Centers for Disease Control and Prevention [CDC] 2008). A knowledgeable public health workforce includes understanding of cultural competence. Cultural competence is a set of congruent behaviors, attitudes, and policies that are developed and implemented in an agency that enables effective work in cross-cultural situations (Cross et al. 1989). Without cultural competency, public health still struggles to close health disparities.

## Cultural Variables

Anthropologists use a number of variables to consider different cultures. These variables include demographics, degree to which the culture incorporates technology, type of economy, social structuring within the group, political organization, and role of religion (Ember and Ember 1990; Scupin and DeCorse 1998; Whitten and Hunter 1990). Behavioral aspects of culture include social structure, and symbolic aspects include components such as religious beliefs and practices (Scupin and DeCorse 1998). Social structure is the pattern of relationships within society that provides the basis for all relationships. It includes such components as social status, kinship, gender, and age (Dynneson 1977; Kassebaum 1985). Religion is a cultural aspect that is shaped by the population's history and by social structure (Gerrard, Bredda, and Gibbons 1990; Nash 1990; Scupin and DeCorse 1998). Religious beliefs often affect and reflect the sociocultural conditions and concerns of the population (Scupin and DeCorse 1998).

Hall (1976) asserts that one of the functions of culture is to provide a selective screen between man and the external world, and that culture designates what one pays attention to and what one ignores. Within a culture, one's awareness of the screen exists on a continuum. Some cultures pay more attention to the surrounding circumstances or the context in which an event occurs. The interpersonal event is interpreted with reference to contextual variables such as social status, relationship, history, and social setting as well as factors such as tone of voice, gesture, personal attire, and posture. In contrast, other cultures tend to screen out many factors and focus is placed more strictly on the basic objectives of the interaction. Speed and efficiency, as opposed to other factors, are central to the nature of the interaction.

In the routine of our daily lives, we constantly move along the context continuum, but where we operate most frequently and most comfortably depends mostly on our culture, and the learned behaviors acquired from our cultural group. The following statement serves as an oversimplified illustration of this point: Hispanics, African Americans, Native Americans, Asians, people of Mediterranean descent, and people in rural areas tend to be more contextual, while as a general rule the cultures of Scandinavia, Germany, Anglo-Saxons, and inhabitants of large metropolitan areas tend to be less context-driven. Cultures that are more contextual, according to Hall (1976), have a tendency to be group oriented and more respectful of formality and hierarchy. For context-oriented cultures, cooperation among individuals is emphasized, time is flexible (polychromic), and indirectness in conversation is considered a form of courtesy. By contrast, cultures that are less contextual generally tend to focus on the individual and competition is encouraged. The concept of time is much more rigid (therefore everything is scheduled, and change on the run is often disruptive and unacceptable), and directness in conversation is considered a virtue regardless of how crude the content. While these two kinds of cultures differ, neither is inherently better or valuable. Instead, the concept of the context can be used as a valuable tool to understand a culture and its relationship to behavior and values.

With this in mind, it is possible to understand why the construct of disability and individuals with disabilities are perceived and treated differently by different cultures. It is

also possible to understand why groups and societies that are more individual-oriented (versus communal or group) may tend to focus more on facilitating the independence and self-determination of the people with disabilities, especially through incorporation into the mainstream of the economy and labor markets. In contrast, societies that tend to be more paternalistic may also be very protective of individuals with disabilities, sometimes to the point of marginalization or discrimination from the activities of the rest of the community. For example, Smart and Smart (1991) report on studies of Hispanic families they describe as overprotective and paternalistic toward their family members with disabilities. Even in cases where the family member with a disability wanted to be independent and self-sufficient, they were seldom allowed to do so by their families. The determining influences for the families were traced to an enlarged sense of responsibility that the family felt toward the family member with a disability. In other cases, the family felt shame, or the family was reluctant to allow the person with a disability to be independent based on the perception that society would criticize the family and consider them inhuman, insensitive, or lacking love for people known as the “minusvalido.” The term “minusvalido” literally means in Spanish “of less value” or “invalid,” but it is commonly used in many Spanish-speaking countries to designate a person with a disability.

Another author whose theories also serve to provide explanations regarding the social attitudes toward people with disabilities is Hofstede (1997, 2001). For Hofstede, culture is learned, not inherited, and it implies a “collective programming of the mind which distinguishes the members of one group or category of people from another.” In studying the influence of culture in organizations, Hofstede introduced the concept of the “global dimension of national cultures.” A “dimension is an aspect of a culture that can be measured relative to another culture.” Hofstede identified four dimensional aspects that can be measured and compared between cultures: 1) power distance, 2) collectivism versus individualism, 3) masculinity versus femininity, and 4) uncertainty avoidance. Together these form a four-dimensional model of differences among cultures. For Hofstede, individualism “pertains to societies in which the ties between individuals are loose: everyone is expected to look after himself or herself and his or his immediate family.” Collectivism is considered to be at the opposite end of the spectrum; therefore it “pertains to societies in which people, from birth onwards, are integrated into strong, cohesive groups, which throughout people’s lifetime continue to protect them in exchange for unquestioning loyalty.”

As a result of his research, Hofstede developed the “individualism index value” (IDV) for 50 countries and three regions. In this research, the higher the IDV score, the more “individualistic” the society and the lower the IDV score, the less individualistic and the more “collectivist” the society. Taking these factors into consideration, it is possible to realize the many challenges that public health professionals face in countries such as the United States of America where population growth and demographics have dramatically changed the composition of the population. The concepts of cultural differences on key human factors such as individualism and power are useful in understanding behavior, and in helping public health professionals create a useful framework for developing consumer relationships that minimize the misunderstandings germane to transcultural communication.

## Culture: Interpretation and Treatment of Disabilities

A cross-cultural perspective is an interpretation on the basis of comparing across multiple groups and looking for differences between those societies having and those lacking particular characteristics (Ember and Ember 1990). The rationale behind taking a cross-cultural view of disability is to better understand the social forces that shape lives (Banks and McGee Banks 1989). A multicultural perspective provides a way of understanding people from diverse cultures and encourages us to look at how values and perspectives affect how people interact with others and how they view the world. A contemporary perspective of disability that is emerging in many cultures asserts that persons with disabilities are far more limited by their economic, social, and cultural circumstances than by their specific physical, sensory, psychological, or intellectual impairments (Groce 1999). This makes disability inherently a culturally mediated phenomenon.

Most societies have explanations for why some people are disabled and some are not; how the disabled should be treated, what their rights, responsibilities, and appropriate roles are. Groce (1999) has identified three factors that influence cultural perspectives of disability: 1) causality, 2) valued and devalued attributes, and 3) anticipated adult status. Causality refers to cultural explanations of disability and its root causes. How cultures view and treat their members with disabilities is often related to how or why an individual is perceived as having become disabled. For instance, a person without the function of the lower extremities (i.e., paraplegic, amputee, etc.) may be viewed and treated differently if the disability is the result of an injury of war (in which case the person may elicit great respect) or whether the individual was born with the condition (resulting in less respect). A blind elderly person may be perceived differently than a teenager with the same limitation. While the elder might be treated with deference or sympathy, the youngster might be the subject of jokes and teasing.

In some cultures, the birth of a child with an identifiable disability may be seen as a punishment from God that the parents or their families have earned for their past sins. Explanations related to “divine displeasure,” witchcraft, evil spirits, and genetics have been discussed by several authors including Groce (1999) and Ingstad (1995). In other cultures such as those found in Botswana and northern Mexico, the birth of a child with disabilities may be seen as God’s trust in the parents to care for a delicate child (Groce 1999; Madiros 1989).

In a number of cultures, the social impact of a disability in a family may stigmatize the family and the siblings of the individual. In such cultures it is common to “hide” disabled family members from public to avoid the inference of a possible genetic disorder in the family. In many of these cultures, the location of the individual in the sibling order is also important, with the first male offspring often subjected to a more inquisitive scrutiny than subsequent members of the family.

## The Importance of Cultural Attributes

Different attributes are valued or devalued by different cultures. As Groce (1999) notes, “In societies in which physical strength and stamina are valued, individuals

with physical impairments are at a disadvantage. In places where intellectual endeavors such as literacy and the ability to use technology are important, the fact that one is a wheelchair user may be less limiting. Similarly, in some Pacific island societies, in which a man's status (but not a woman) is determined in part by his ability to speak well in public, deafness or a speech impediment will be judged particularly disabling."

In a cross-cultural study that included Chinese, Italian, German, Greek, Arabic, and Anglo-Australian communities, Westbrook, Legge, and Pennay (1993) found that there were significant differences in attitudes toward persons with disabilities. German, Anglo-Australian, and Italians were found to be more accepting of people with disabilities. However, one of the most important findings by the authors was the relative degree of stigma attached to the various disabilities. For instance, people with asthma, diabetes, heart disease, and arthritis had the highest levels of acceptance, while people with AIDS, mental retardation, cerebral palsy, and psychiatric illnesses had the lowest levels of acceptance.

The willingness of societies to allocate resources and care to a person with disabilities is often dictated by the potential attributes that the person may have as an adult. For instance, nomadic tribes may consider persons with movement impairments, such as the elderly, a burden to the social group and may leave behind individuals unable to fend for themselves or assist in providing for the group. Likewise, patriarchal, male-dominated groups and societies that limit the participation of women in the central functions of everyday life, may not offer the same opportunity for treatment, rehabilitation, and social incorporation for their women as they do for men.

## Historical and Cultural Approaches to Disability

Traditional beliefs about disability from developing countries include stories about persistent neglect (Ingstad 1999). In ancient Greece, infanticide was a common treatment for the newly born with physical defects and other perceived disabilities. The practice is still found among the Mehinaku Indians in Brazil where twins, illegitimate children, and those born with physical defects are not only taboo, but a source of shame to the parents (Scheper-Hughes 1990). Mull and Mull (1987), who spent time among the Tarahumara Indians of the Sierra Mexico, observed several cases of parental rejection of children with deformities and malformations. According to Tarahumara traditions, these children put the whole community at risk of serious illness and allowing the children to die was thought of as a public health responsibility. Scheper-Hughes (1990) also notes that "selective neglect" is a form of passive infanticide used by several cultures around the world to dispose of those children deemed unfit to face the struggles typical of human life. While one might be quick to believe that such cases are relegated to developing countries and tribal nations, stories that include neglect and even murder of infants with disabilities also are found in developed nations and have been documented from authoritative sources such as the World Health Organization (WHO) (Ingstad 1999).



## Disability: Race, Ethnicity, and Culture

Different cultures have different interpretations for the causes of disabilities and how the person with a disability is ultimately treated. In the United States, Caucasians, Hispanics, African Americans, Native Americans, and Asians constitute the largest racial and ethnic groups. Each of these groups exhibit particular attitudes toward disabilities and persons with disabilities. As Paniagua (1998) points out, among African-American families, both the nuclear family—parents and children—and the extended family of relatives, friends, and community members are important factors in the problem-solving and decision-making process of the group. It is common to see families rally around a child with a disability and even take turns to care for family members with disabilities. Education of the family and financial considerations will play an important role in the degree and quality of care that the disabled receives.

Hispanics currently represent the fastest growing segment of our population and, because Hispanic refers more to the heritage of an individual, such a person could be of any race. The multicultural nature of this group makes it complex and difficult to find commonalities in behavior that would apply to the majority of its members. Smart and Smart (1991) identified five factors that may be associated with the acceptance of disabilities among Mexican Americans: 1) a familial cohesive, protective society; 2) a stoic attitude toward life in general; 3) well-defined gender roles; 4) religious view; and 5) reliance on physical labor. With these general factors in mind, some Mexican-American families are seen as overprotective of family members with disabilities to the point that others, such as White professionals, consider it isolation. Religious beliefs also combine with resignation and stoicism, resulting in an attitude of “this is the will of God and one must accept it,” or “such is life, and the pains and problems are to be faced with courage since nothing can be done to change it.” Similar to some racial and ethnic groups, disabilities may be viewed as having a supernatural cause or origin, resulting in a type of isolation for persons with disabilities that is both physical and emotional. In a society where the gender stereotype and roles are well defined, the “macho” image of the Hispanic male tends to translate into a feeling that if he has a disability he will lose respect and status in the social group. Smart and Smart (1991) suggest that Hispanic men with disabilities may believe that their life is devastated if they cannot assume the role of provider in a family. Frequently, work accidents and some forms of disability will be hidden since seeking help for any suggestion of pain may be interpreted as a sign of weakness. Even when treatment is sought, it is commonly discontinued after the signs or symptoms have subsided and the person can resume daily activities. Treatment of minor discomforts or problems that are not life threatening may be viewed as socially unacceptable.

While culturally very different, Asian and Hispanic groups share many of the same views regarding disabilities and the disabled person. For both, the nucleus of the family can be the center for individual problem-solving and decision-making. Parents can determine their children's destiny by deciding career paths, and even their social milieu. Asian women are expected to be obedient and respectful of their fathers and husbands. Children must always respect their parents and family elders.

Some conditions that may qualify as disabling in western societies are conceived differently in Asian society. For instance, deformity of the feet caused by binding or the altered states associated with epilepsy is considered a gift among some Asians (Cheng 1990).

As is the case for Hispanics, understanding the culture and language communication are key in the proper diagnosis and treatment of disabilities of Asians. It is important to note that Asians are very private about their problems and family matters; therefore many do not talk openly about them in public (let alone in support groups) or even feel comfortable sharing them until a relationship of trust has been developed. Language can be a major barrier. The symbolic nature of some of the Asian languages, coupled with very complex grammatical structures, can lead to confusion, misinterpretation, and misdiagnosis.

Language also plays a very important role in the communication between the individual with a disability and public health and health care professionals. Understanding the nuances of the language, the translation and interpretation of words, sentences, and statements is critical to the proper assessment of an individual's needs. When necessary, the use of professional interpreters can bridge the cultural and language voids when patient and provider do not communicate in the same verbal language. Understanding and interpretation of body language and the nuances of the different cultures are also critical skills when dealing with persons with disabilities.

Cheng (1990) recommends the following guidelines for successfully interacting with Asian/Pacific individuals and families:

- Interactions should be formal and proper.
- Professionals are held in high regard and credibility is paramount to building a strong provider-client relationship. It is best when professionals establish their roles and that of the family through a formal introduction (preferably made by a third party). The introduction should include a brief mention of the professional's degrees, experience, and credentials. After the introduction, the physician or professional is expected to assume the role of authority figure.
- The role of the family as actively participating in the decision-making process is an unfamiliar concept to many Asians. Asking for their input may cause questions about the competence of the professional.
- Expect no-shows or the whole family showing up for the appointment. Punctuality is not regarded important as most Asians fall into the "polychromic" category.
- Since life is circadian and organized by the rising and setting of the sun and the planting and harvesting of crops, events such as birth may be recorded accordingly (e.g., birth occurred during the planting season).
- Avoid direct questioning; it may be construed as confrontational, threatening, or impolite. Direct eye contact might be considered rude and an invasion of privacy. An indirect communication style, with paid attention to verbal and nonverbal cues, might yield the best results. Asians and Pacific Islanders tend to use body language, such as head nodding and minimal verbalization, as a show of respect to authority figures.

- Avoid using jargon and professional language that might be the source of confusion and misunderstanding in the communication.
- Most Asian cultures are patriarchal and male dominant, therefore the father has preferred status and often the final word. The concept of self-determination is foreign to most Asians.
- Do not rush families into decisions.

It is important to consider the social impact of the family's decisions. In many cases, a visible physical or structural abnormality could bring shame to the individual and the family. Saving face is greatly valued and important to the traditional Asian family.

Although based on cultural generalities, it is noteworthy that most of the previous guidelines would also be applicable to other cultures as well. One such group is Native Americans. According to the census of 1997, there were 339 federal and state-recognized Native American tribes, 227 federally recognized Native entities in Alaska, and over 175 languages spoken by these groups. These tribes share the same historical fate after the colonization of the territory today known as the United States of America, but different tribes have different cultures, speak different languages, and many have their own unique beliefs regarding life, death, and after death. There are also distinctions between Native Americans who live, or have lived most of their lives, within the territory of a reservation, and those who have migrated into non-reservation urban and suburban life.

Native Americans are also very diverse. One study that examined the Native American experience with disability acknowledged the diversity within the Native American community and argued that it was important to do community level research that included public forums, focus groups, and ethnographic interviews (Marshall and Largo 1999). The authors noted that, in general, Native Americans preferred to be treated by Native American health care personnel because they can relate to the nuances and idiosyncrasies of their culture. In fact, a number of ethnic and racial groups prefer to receive health care from individuals from their same cultural background (Saha 2000). It is not only that the patient or client may feel more comfortable in front of a person of their same gender or culture, but that the possibilities of misdiagnosis are reduced. For instance, Johnson et al. (1988) explained that a Native American, who may, as a matter of respect, avoid direct eye contact, shake hands with a slight touch, and show nonverbal communication styles considered in the western culture as "slow," could easily be diagnosed with depression. To complicate matters even more, American Indians have said in surveys that in their Native languages there is no word for disability. The focus is on the part that the individual can play in society, not what might be wrong with his or her body (Marshall and Largo 1999). Public health professionals may be challenged by attempting an exchange about disability with Native Americans for whom the concept of disability does not exist.

To complicate matters further, different cultures and countries may have different perceptions and diagnosis for the same condition. Draguns and Tanaka-Matsumi (2003) reported on the earlier studies of Cooper et al. (1972) and Draguns (1973). In the former, schizophrenia was found to be more frequently diagnosed in New York than in London, and, conversely, depression was more "prevalent" in London than in New

York. The authors note that “In the more frequent instances where mixed symptoms were presented, Americans opted for [the diagnosis of] schizophrenia and Britons, for affective disorder.” Draguns recognized that “not only patients, but mental health professionals and community as well as institutional settings, may contribute to the differences across cultures.” Cooper et al. (1972) discovered that these diagnostic differences disappeared when the standardized diagnostic system (ICD-8) of the World Health Organization was used by all practitioners involved in the project. If such divergence in the diagnosis of the same condition can be found across cultures that share many similarities and roots, such as that of Britons and North Americans, much more conflict of opinion can be expected to occur when vastly different cultures are involved.

Similarly, standardized assessments of health may have limitations when used cross-culturally. Gannotti and Handwerker (2002) note the importance of validating the cultural context of health in order to obtain accurate and useful information from standard instruments. A person might appear taciturn, shy, uninterested, or unable to utter words to a health care provider. This in turn may be interpreted to be part of a “mental condition” of the patient, while in reality, coming from a Hispanic (or Native American or Asian), such attitude, as one would expect, is a manifestation of deference and respect toward a member of a “dignified profession.”

## Cultural Incongruity

One of the keys to successfully interacting with patients/clients of diverse nationality, ethnicity, or place of origin is “avoiding cultural blind-spots.” Buchwald et al. (1994) suggest that “Whether cultural differences will play a role in providing care to a patient from another culture is not always obvious.” Incongruity is more likely to be noted when the cultural gap is wide but may contribute to superficial generalizations and cultural stereotyping. This is especially important because of the wide variation within ethnic groups. At the other extreme is the cultural blind spot syndrome. Just because an individual looks and behaves much the way you do, you assume there are no cultural differences or potential barriers to appropriate care.

A key concept for avoiding cultural incongruity pitfalls is for the public health professional to understand the distinction between ideological and behavioral ethnicity. Many Americans of European origin nominally identify with their ethnic heritages. These ideological ties, however, generally do not condition their health behaviors and beliefs. The opposite is true of behaviorally ethnic individuals. Their cultural background often profoundly affects their daily actions, and their attitudes and outlook on health and illness are likely to clash with those of the biomedical perspective.

Attention during the interactions to some predictors of behavioral ethnicity may help public health professionals judge the likelihood that cultural factors will be an important element. Johnson, Hardt, and Kleiman (1994) developed “predictors of behavioral ethnicity” as follows:

- Emigration from a rural area
- Frequent returns to the country of origin

- Inexperience with Western biomedicine and the health care system
- Lack of or limited formal education
- Little knowledge of English
- Low socioeconomic status
- Major differences in dress and diet
- Recent immigration to the United States at an older age
- Segregation in an ethnic subculture.

Understanding that different cultures have different, sometimes contradicting, concepts of disabilities; that culture plays a pivotal role on how the person with disabilities will be treated by society; that within the same culture there are individual variations; that time spent within another culture and acculturation will contribute to the variety of individual behaviors; and the importance of avoiding stereotyping and the “cultural blind-spots” will increase the treatment and understanding between providers and patients/clients from different cultures.

## Contemporary Disability Experiences

In the majority of developing nations, disabilities have not been a national priority because of other more pressing problems such as famine, war, political instability, and economic depression (Nagaswami 1990). In developed and industrialized nations, attention on disability issues largely center on accessibility, antidiscrimination laws, social services, and self-determination. In many nations, concerns are expressed about the need for laws and enforcement, allocation of financial resources destined to persons with disabilities, accessibility to health care and education, and general education of the public regarding disabilities.

For newer countries such as Canada, the United States, and Australia, the issue of architectural barriers and accessibility is more easily addressed than in Europe and Asia, where numerous structures, buildings, and monuments are hundreds and even thousands of years old. New constructions can be “built to code” that take into account the disabled user. During the decades of the 1980s and 1990s, the European Union (EU) made significant progress in making its monuments and history accessible to people with physical and sensory disabilities. For instance, the Louvre Museum in Paris, France, has been furnished with elevators, ramps, and platforms that permit circulation on a wheelchair through most of the museum. Audiotapes in different languages can be used by persons with visual impairments to “tour” the museum, and toilets with room for maneuvering assistive devices can be accessed. In Madrid, Spain, the museum Reina Sofia has cleverly integrated modern elevators located outside the façade of the building, making it both functionally accessible and aesthetically pleasing. In many major cities, the traffic lights will emit a clear sound indicating to persons with visual impairment that they have the right of way. However, most of the old structures in Europe and the United States still remain inaccessible to people with mobility limitations. How does a person with mobility limitations reach the top of La Giralda

in Seville, Spain, Il Duomo in Firenze, Italy, or even the Washington Monument in Washington, D.C.?

In the 21st century, societies around the world face many challenges with regards to disabilities and the services and treatment that the person with disabilities receives. In part, the challenge is political and economic. Many developed countries have passed antidiscrimination laws relating to disability, but fail to fully implement or enforce them. Other countries, mainly sub-Saharan nations and other developing world countries, continue to face famine, war, and economic depression. Their priorities continue to be provision of food, education, basic health care, and housing to the general population, with few resources targeted to supporting the needs of persons with disabilities. Yet, culture and cultural attitudes will continue to shape the present and future of the disability movement around the world.

The role of the state and the family in the care of people with disabilities also varies between developed and developing countries. Developing countries in general have inadequate provisions for people with disabilities and therefore a great amount of burden falls on the family (Thorburn 1999). Families that are poor and live in precarious conditions can ill afford the expenses associated with caring and long-term sustenance of a disabled person. In addition, if the contribution of the state to the general care and education of the person with disabilities is all but absent, then the burden to the family often leads to the neglect of the individual.

Although the passage of the Americans with Disabilities Act in the United States has afforded many gains to people with disabilities in this country, disability issues and disability programs in Europe differ from U.S. counterparts in almost every aspect including program design, definition of disability, population covered, and eligibility requirements. One study by Zeitzer (1994) looked at disability protection in five European countries (France, Germany, The Netherlands, Sweden, and the United Kingdom). The study found that a country's expenditure on social protection programs like disability protection can greatly affect the lives of the disabled. The United States spends the smallest percentage of its GDP on these expenditures and has the least comprehensive program among the industrialized nations (Zeitzer 1994). Many of the disparities that Americans with disabilities face are nonissues to Europeans who are covered by comprehensive, universal health insurance programs (Zeitzer 1994). These programs provide virtually everything that a person with a disability needs, including doctor visits, hospitalization, and equipment (Zeitzer 1994). Unlike in the U.S., equipment such as prosthetics in many European countries are virtually free, and "cash-sickness" payments replace income loss due to the condition in a matter of days (Zeitzer 1994). For a more detailed overview of the services and policies in the U.S., please see Bersani and Lyman (this volume).

## Conclusion

Disability is a term broadly used throughout the world to designate a physical, mental, intellectual, or sensory impairment of an individual. How their fellow members

of society perceive individuals with these impairments or limitations depends on the culture of the group where the disabled individual lives. Disability in itself is a relative factor often defined by the person's ability to "disguise" it in front of other individuals. What makes a person disabled might be a matter of legal terminology or definition more than the limitations that the disability might impose on the individual. Wainapel (1999) states, "There are doctors who cannot hear, and those who are deaf to the appeal of the patients. There are doctors who cannot move, and those who are immobilized by prejudice or rigid attitudes. There are doctors who cannot see, and those who are blind to the limits of their own competence. Which of these is the more handicapped?"

Culture plays a key role in society's response to disabilities and the treatment and integration of the disabled into the mainstream of society. Causality, valued and devalued attributes, and anticipated adult status are determinant in how societies perceive and respond to persons with disabilities. Culture also shapes the dimensions and severity of particular conditions or diseases through the socially constructed meaning of the disability and its impact to other members of the individual's living circle (Gannotti and Handwerker 2002).

Prognosis, physical appearance, and the cultural notion of beauty also impact the perception of society regarding the individual with disability (Strauss 1990). For instance, children born with a cyanotic condition such as pulmonary valve stenosis or a right-to-left ventricular shunt may, as a result, have to substantially limit their physical activity and participation in sports even after corrective surgery. However, the "cultural standards of beauty" may stigmatize a girl who has undergone plastic reconstructive surgery to treat congenital cleft palate.

Many societies and developed nations are more likely to implement programs aimed at helping the disabled participate as productive members of society, who are able to provide for themselves and contribute to offset some of the social costs of their treatment or rehabilitation. In contrast, in other societies and developing countries, economic constraints and cultural beliefs may combine to make it much harder for an individual with a disability to acquire any sense of independence. While "society" feels it has the responsibility for the welfare of disabled individuals, the centralization of government functions and the people's notion of the "government as a social problem-solving entity" leave the burden to a system whose treasury vaults have often been dilapidated by the actions of poor administrators or devastated by internal and foreign conflicts.

Industrialized nations have recognized the importance of caring and protecting persons with disabilities against various forms of discrimination. Various forms of legislation have been implemented, yet there is much work to be done. Ingstad (1999) noted, "In recent years, however, many people with a disability in developing nations have become more vocal and able to speak for themselves before the authorities." She continues, "We should not forget, however, that these spokespeople are usually an elite as far as education and ambition is concerned, and do not represent the needs of poor people with disabilities living in rural areas of developing countries."

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