

Disablility and the Other in Cultural Anthropology

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"Culture is and culture is relative. What we term "anthropology" is that region which opened up in the field of knowledge in virtue of the recognition of **the being** of culture, by means of, or on the occasion of, the recognition of the existence of other cultures."

(McGrane 1989: 117)

In *Beyond Anthropology: Society and the Other*, Bernard McGrane (1989) traces the historical development of Western views of non-European peoples and their customs, for which he uses the general term "the Other." He writes that during the Renaissance the differences displayed by the non-European Other were seen as the result of a connection with demonic and infernal powers. In the Enlightenment, distinctiveness was attributed to the Other's ignorance and superstition, as opposed to European rationalism, and in the nineteenth century it was interpreted as being characteristic of a state in the evolutionary development of civilization of which Europe was the most progressive form. It was not until this century, says McGrane, that the Other's difference was seen as an expression of "cultural diversity" (McGrane 1989: 113). According to McGrane, recognition of the "being of culture" was a necessary condition for the development of cultural anthropology, a discipline of social science which sets as its goal the systematic examination of human cultural diversity (McGrane 1989: 117).

Since the middle of the century anthropologists have begun to explore the heterogeneity and presence of "otherness" in First World societies (Mead 1942, Vidich 1958, Liebow 1967). The findings of these ethnographers caused a change in anthropological metaphor: rather than a melting pot,

they argued, modern Western societies such as that of the United States resemble a rich mosaic of cultures, each of which constructs its unique identity based on ethnicity, gender, class, occupation, sexual orientation, social group, and other characteristics or traditions. To be a stranger, anthropologists learned, one does not necessarily have to travel to a new geographical location; an anthropologist can be an outsider within her/his own neighborhood or country (Barrett 1991:16).

Implied in the contemporary idea of national cultural diversity is an assumption that the Other can be found all around us. Anthropologist and former missionary Elmer Miller describes in his autobiography, *Nurturing Doubt* (1995), how through a series of experiences living in different cultures he found himself a stranger to all of them, including those of his own country and his chosen discipline. Miller says that although he became enthusiastic about each new direction in his life (e.g. religious, professional, theoretical), he eventually always came to doubt its exclusive claims to knowledge and the truth. In the Mennonite community in which Miller grew up, the idea of a pilgrim was basic to the culture's sense of identity as separate from the surrounding society. Miller connects this notion to the work of Lévi-Strauss, who called doubt "the philosophical attitude par excellence" (Lévi-Strauss 1976:26): "A pilgrim is someone in a strange land around people and practices that appear unfamiliar, even uncomfortable.... Pilgrims know that they are not fully at home in their physical and intellectual surroundings and, consequently, are never in full control. Such awareness modulates their responses to per-

sons and ideas recognized as different from their own" (Miller 1995:7, 203). At the end of his book, Miller expresses the hope that such modulation can contribute to the improvement of interpersonal relations, and by extension intercultural interactions, so that we may construct "more sane and safe societies" (Miller 1995:203).

"Culture [is] the system of **agreed-upon** meanings, that serve as recipes, or guidelines, for behavior in any particular society. To say "agreed upon" is equivalent to saying **symbolic**, since a symbol is something whose meaning is bestowed upon it by those who use it" (White 1940:453, in Barrett 1991:55).

Two years ago, when I began to work as a personal assistant¹ for people with developmental physical disabilities, I encountered people whose communication systems, physical functions, network of friends and institutions -- their "symbolic system of meanings," in Barrett's words -- I did not understand. My first assignment was to help one student and one faculty member who each had cerebral palsy. My tasks included helping in the bathroom, in dressing/undressing and washing, assistance in eating, transportation, telephone communication, performance of clerical tasks, and some tutoring. Both teacher and the student were unable to use their hands or legs for independent functioning, and they had different degrees of difficulty in speech. Until I had learned to understand the electronic devices with which they worked and the signs they used to speed up their communication, I felt like someone in a culture thousand of miles away from home with no knowledge of the native tongue.

Through my work as a personal assistant, I developed a deeper interest in disability as a social condition. My study and observations created a new perspective with which I could understand current anthropological discourse, especially the problematic concept of the Other in relation to the anthropologist. To the able-bodied, disability

connotes imperfection; the disabled are assumed to lack some ability or condition essential to existence as full human beings. Disabilities often inspire fear and contempt among people who are not disabled. Some anthropologists confess to feeling similar emotions about non-Western peoples and their customs upon arrival in their chosen culture of study (Anderson 1990, Chagnon 1992).

Anthropologists can, nevertheless, eventually return home once they complete their research². There is, however, no such return when the Other are people with disabilities. Disability transcends time, space and civilizations, there is no escape from it, no "home" to which to return. People of any ethnicity, any nationality, any class, any age, or any gender can become disabled. Fewer than fifteen percent of all disabled Americans were born with their disabilities, the rest acquired them later in life (Shapiro 1993:7). In fact, disability is an inseparable condition of aging, a process of bodily deterioration common to all living beings. Although unacknowledged, the threat of becoming disabled is always with us.

"The disabled serve as constant, visible reminders to the able-bodied that the society they live in is shot through with inequity and suffering, that they live in a counterfeit paradise, that they too are vulnerable. We represent a fearsome possibility" (Murphy 1990:116).

It is the knowledge of this possibility, Murphy suggests, that causes societies to resent the disabled and marginalize their existence.

United States census data from 1990 indicate that there are about 49 million Americans with disabilities³. The United Nations estimated that 10% of people in the world have a disability (Bryen 1996:1). The number of disabled in this country is growing apace, due especially to the declining birth-rate and the increasing proportion of the elderly, who constitute about one-third of all disabled Americans (Shapiro 1993:6).

Advances in medical technology also help people stay alive longer despite severe disabilities. The disabled are sometimes called "the largest minority in the United States" (Bryen 1996:1, Shapiro 1993:7). Yet, it is a minority that despite its growing size, seems to possess a strange ability to remain almost unnoticed by society. "People with disabilities have been a hidden, misunderstood minority, often routinely deprived of the basic life choices that even the most disadvantaged among us take for granted" (Shapiro 1993:11).

Even anthropologists, specialists on studying groups "invisible" to dominant cultures, have not discussed people with disabilities nearly as much as other minorities, including women, African-Americans, and homosexuals. A memorable exception to this is the work of the late anthropologist Robert Murphy, a professor at Columbia University in New York and author of several books and many articles on the native cultures of Africa and the Americas. In his forties, Murphy was diagnosed with a terminal tumor in his spinal column. With the growth of the tumor, Murphy became increasingly paralyzed, from minor problems in his left leg to complete paralysis of his entire body culminating in death. As a result, he spent more than ten years conducting research on disability, and wrote an autobiography about his life with paralysis called *The Body Silent* (1990).

Murphy calls the disabled "subverters of an American Ideal," and "quintessential American anti-heroes," because they fail to fulfill the central values in American culture which he identifies as "independence, self-reliance, and personal autonomy" (Murphy 1990:116). The majority of people with disabilities in the United States are poorer, less independent and less well educated than any other identifiable group. Fifty-nine percent of adults with disabilities live in households with a total income of less than \$25,000 and twenty-five percent of them receive all per-

sonal income from benefits and insurance programs. Two thirds of Americans with disabilities are not working, yet eight out of ten report they want to work. Most of them stay at home, however, for fear of losing their Social Security Insurance⁴. The majority of the disabled are therefore not tax-payers, but tax-recipients; their very lives depend on the able-bodied majority. As such, they do not fit image of the lone individual who overcomes all obstacles to success with no help from others. As absolute independence is a cornerstone of American mythology, the disabled serve as "quintessential American anti-heroes" (Murphy 1990:116). As "Subverters of an American Ideal" (Murphy 1990:116), they are seen as deviant, and society attaches to them a stigma of marginality. In the face of this stigma, however, the disabled, like other minorities before them, have joined to demonstrate their self-awareness as a neglected group⁵.

In the 1960s and 1970s, the Independent Living Movement was founded by Ed Roberts, a student at the University of California at Berkeley, to fight for de-institutionalization of people with disabilities⁶. The Independent Living model rests on the assumption that disability is not only a medical, but also, and perhaps mainly, a social condition. As such, Roberts argued, it is furthered when the disabled are kept dependent in hospitals and medical institutions. By the same token, many of the harmful social and psychological effects of living with a disability can be lessened when the disabled are entitled to the same rights as other citizens. An important result of the Independent Living Movement's fight was a paradigmatic shift in the definition of "independence." Independence, according to the activists, "is not measured by the quantity of tasks one can perform without assistance, but the quality of life one can have with help" (Zola 1987: vi). After twenty years of continuous struggle, today thousands of the disabled and the eld-

erly have left institutions to live in the Community.

The term "Community", as used by people with disabilities, refers to life outside of institutional care, possibly but not necessarily together with other disabled people. I would like to propose, however, that once people leave institutions, they create a new community of people with disabilities -- one no longer defined by spatial proximity, but rather by both formal and informal networks of people and a shared sense of identity as disabled individuals in non-disabled society. They meet on special transportation vehicles, in entrances and elevators for wheelchair users, in psychiatrists', doctors', and counselors' offices, in day centers, in segregated schools, in activist groups and elsewhere. The Community they create in this manner could also be termed a culture, because within it, or within its sub-communities (defined mostly by the nature of the disability), people share what White and Barrett (White 1940: 453, in Barrett 1991:55) call symbolic meanings: ways of communication (such as sign language used by the Deaf), literature on disability, patterns of the history of disablement (hospitalization, rehabilitation, struggle with insurance companies, rallies defending legislation against further institutionalization and in support of community-based support services), and institutions with which they come into contact (Office of Vocational Rehabilitation, various assistive technology agencies, lawyers specializing in disability-related anti-discrimination suits).

In 1990, as a result of long-term lobbying, disabled Americans succeeded in obtaining the passage of the Americans with Disabilities Act (ADA). The ADA is a legislative anti-discrimination act whose importance for the disabled is frequently compared to that held by the Civil Rights Act for African Americans⁷. Patterned after the Black Pride slogan "Black is Beautiful," some people with disabilities today say, "Disability

is Beautiful," and many of them state that they would not accept a "magic pill" that would get rid of their disability. They show that disability is an integral part of who they are, and to abandon it would be comparable to rejecting one's ethnicity for another. The Deaf community has demonstrated the proximity between ethnicity and disability by writing Deaf with a capital "D," to show that to be Deaf is similar to being an American or African-American in its impact on personal and social identity (Shapiro 1993:74-104). From an anthropological standpoint, the study of disability suggests that the roles of physical and social causes in the construction of cultural identity are closely related.

One of the most intriguing aspects of disability is its double nature as a somatic condition and as a source of social identity (Murphy 1990:195). We tend to erroneously consider the innate physical condition of disability to be the cause of the marginalized social status of people with disabilities. The same logic has been applied in explaining the lower social status of women in most societies; arguing that female physical characteristics and women's natural role as mothers prevent them from performing tasks considered prestigious by a given society. Feminist scholarship has demonstrated, however, that it is the male-dominated society that designates those jobs traditionally performed by men as more valuable for society's well-being (Fernández-Kelly 1983, Bradley 1989, Leacock 1986). An important example comes from the countries of the former Soviet bloc, where women under the communist regimes gained access to many formerly male-dominated jobs. Many of these previously prestigious professions, such as those of doctors and teachers, however, were rapidly devalued after women gained numerically significant membership (Eisenstein 1993: 311). A male-dominated society attached inferior meaning and value to women's labor, regardless of the importance of the task per-

formed. Similarly, it is not so much physical dysfunction that makes people with disabilities necessarily dependent on society, but rather the perceptions and prejudices of an able-bodied majority.

As feminist movements have done for women, the disability rights movement in America has proven that the social standing of people with disabilities can change once the social context changes. Given the opportunity to live in the Community, most people with disabilities can work and become taxpayers. In its emphasis on disability as a source of diversity, as opposed to an impediment or handicap, the disability movement has also demonstrated that living with a disability can be a unique cultural experience. By living in mainstream society, people with disabilities force us to confront another challenge to our belief in our own "belonging." By assuming a permanent position in our society, people with disabilities compel us to abandon our comfortable distance, and to see instead an approach to life equally valid in its difference. The presence of the disabled is particularly important because they remind us of the existence and vulnerability of our bodies, and by extension, of the uncertain basis for our social identity.

Like Miller in *Nurturing Doubt* (1995: 199-203), McGrane closes his book with a critical discussion of Western anthropology (McGrane 1989:113-129). He argues that in studies of different ethnic groups our views of the Other have always been governed by the implied understanding that it was we -- the Western anthropologists -- who knew how to analyze the Other. It was the anthropologist who *spoke about the silent* Other. "In order for modern anthropology to sustain itself, its monologue about alien cultures, those cultures must be kept in analytic silence" (McGrane 1989:128). McGrane criticizes the arrogance of Western anthropology regarding its exclusive claims to truth about different cultures, and like Miller (1995:199-203) sug-

gests that too much self-certainty leads to control instead of understanding (McGrane 1989:123-129). We should all understand that we are strangers in other cultures, and at the same time, by always doubting our own stance and ideas, we should all feel like foreigners (pilgrims) in our own cultures and in the world as a whole. Disability suggests that it is not on the outside, but rather within ourselves that we fear encountering "the Other." We fear the disabled because of their ability to remind us of why *we* can be *them*, of why it is that we are perhaps always pilgrims, strangers in our own land.

Notes:

1) The World Institute on Disability defines personal assistance services (PAS) as follows: "Personal assistance involves tasks aimed at maintaining well-being, personal appearance, comfort, safety and interactions within the community and society as a whole. In other words, personal assistance tasks are ones that individuals would normally do for themselves if they did not have a disability" (Litvak 1987: 12).

2) Anthropologist Maria Vesperi makes a similar observation in the introduction to her book, *The City of Green Benches*, in which she describes an elderly community in St. Petersburg, Florida: "There will be no 'return home' for anthropologists who study their own aged, no resumption of the comforting distances that help us rationalize our place in informants' lives" (Vesperi 1985: 21).

3) The Americans with Disabilities Act of 1990 defines disability in the following way: Title I. Section 1630.2 (g): An individual is considered to have a 'disability' if that individual either (1) has a physical or mental impairment which substantially limits one or more of that person's major life activities, (2) has a record of such an impairment or, (3) is regarded by the covered entity as having such

an impairment.”

“Regulations (h): Physical or mental impairment means: 1) Any physiological disorder, or condition, cosmetic disfigurement, or anatomical loss affecting one or more of the following body systems: neurological, musculoskeletal, special sense organs, respiratory (including speech organs), cardiovascular, reproductive, digestive, genito-urinary, hemic and lymphatic, skin, and endocrine; or (2) Any mental or psychological disorder, such as mental retardation, organic brain syndrome, emotional or mental illness, and specific learning disabilities. Regulations (I) Major life activities means functions such as caring for oneself, performing manual tasks, walking, seeing, hearing, speaking, breathing, learning, and working.” Preamble, Americans with Disabilities Act Handbook. Washington: EEOC and the U.S. Department of Justice, October 1991: p.1.

4) The statistical information in this paragraph comes from the results of a poll prepared by Louis Harris and Associates, 1994.

5) For a history of the disability movement, see Shapiro 1993.

6) Ed Roberts contracted polio when he was young, and became paralyzed from the neck down. He used an artificial lung and a respirator, and became one of the first seriously disabled people who graduated from the University of California at Berkeley. For many years he had been the President of the World Institute on Disability. He became a hero and a role model for the disability movement, and the news of his death two years ago filled the pages of disability magazines and journals.

7) The comparison of the disability movement with the anti-discrimination struggle of

other minorities is relatively common in the disability literature (see for example Shapiro 1993: 7, 11). In his autobiography, *Moving Violations*, John Hockenberry, a former correspondent for the National Public Radio, gives an interesting example of how differently African-Americans and whites in New York interacted with him - a white man in a wheelchair. One day he decided to take subway to work (although it was not accessible): “At this point, every white person I had encountered had ignored me or pretended that I didn’t exist, while every black person who came upon me had offered to help without being asked. I looked at the tape recorder in my jacket to see if it was running. It was awfully noisy in the subway, but if any voices at all were recorded, this radio program was going to be more about race than about wheelchair accessibility. It was the first moment that I suspected the two were deeply related in ways I have had many occasions to think about since” (Hockenberry 1995: 308).

Murphy also talks about how the societal attitudes towards him changed once he started using a wheelchair. Suddenly he was greeted by an African-American policeman who never talked to him before. His relationships with women were now less strained than those with men. His undergraduate students who used to be afraid to talk to him started coming to his office to ask questions, and even touched him sometimes on the shoulder. This suggests that disability really has the power to outweigh other social characteristics and to change normative expectations. Once marginalized through his disability, members of other marginal groups with whom he, as a white male, had had trouble communicating before his disablement started to approach him on more equal terms (Murphy 1990: 127).

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