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Anthropological Theories of Disability

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Anthropology has provided a theoretical context for the study of disability. Social and cultural anthropology and medical anthropology have enriched our understanding of disability. Anthropological interpretations of disability feature concepts of "the other," deviance, and stigma that can expand our interpretations of human behavior in the social environment.

KEYWORDS Anthropology, HBSE, disability

INTRODUCTION

Anthropology is the study of humanity, and it is defined from other social science disciplines by its reliance on cultural relativity as an organizing principle (Frank, 1986b; Ingstad, 1995). The field includes such subdisciplines as archaeology and biological, cultural, and linguistic anthropology. Biological anthropology covers human evolution, primate behavior, genetics, forensics, and medical anthropology (Devlieger, 1998). Cultural (social or sociocultural) anthropology focuses on social and cultural aspects of human experience, including status, religion, law, stigma, and deviance. Linguistic anthropology addressed the variation in languages, focusing on the social aspects of language. Archaeology is concerned with the material remains of human societies.

The field of anthropology has contributed to knowledge about cultural relevance, cultural relativity, and defined the meanings of culture (Klotz, 2003). The concept of culture is important to anthropological study of disability because the lens of culture may be applied to disability in a variety of ways: Disability may be considered a culture, culture may be considered a disability, and cultural norms and values influence conceptions of disability (McDermott & Herve, 1995). Cultural anthropology has particularly focused

on the perspective of the outsider with respect to how different cultures perceive "otherness."

People with disabilities are often labeled "the Other," somehow separate from people who are not considered to have disabilities (Ablon, 1995). The "otherness" of disability is unique, however, because anyone may become disabled at any time (McDermott & Herve, 1995). Anthropology's "genuine fascination" with "the Other" can logically inform the field of disability studies, but this connection has not fully been utilized (Cervinkova, 1996; Edgerton, 1984; Kasnitz, 2001; Klotz, 2003; McDermott & Herve, 1995).

Each subdiscipline of anthropology overlaps with disability studies, and many important contributions to the study of disability are rooted in anthropology. Linguistic anthropologists have studied deaf sign languages and the culture of language, but this has not been a main focus of linguistic anthropology (Fjord, 1996; Groce, 1985; Padden, 2000; Senghas, 2002; Stokoe, 1980; Washabaugh, 1981). Archaeology has contributed to the understanding of disability among prehistoric human ancestors, but this contribution has been limited (Bridges, 1992; Hubert, 2000; Klotz, 2003; Schacht, 2001). Anthropologists note that the field of disability studies used theoretical constructs such as culture, stigma, and status transitions (liminality) to explain and explore disability (Gleeson, 1997; Shuttleworth, 2004).

The largest anthropological contribution to disability studies has come from cultural and medical anthropology. It is universally acknowledged that "some range of physical and behavioral differences are recognized in all societies," but the reactions to those differences vary widely between cultures and communities. (Groce, 1985; Klotz, 2003; McDermott, 1995; Rao, 2006; Scheer, 1988; Shuttleworth, 2004). Disability is a "complex social, cultural, and biomedical phenomenon" (Klotz, 2003). Anthropologists have contributed to the understanding of disability as a sociocultural experience and a physical or mental condition (McDermott, 1995; Scheer, 1988).

Shuttleworth (2004) and others assert that anthropologists have only begun to explore disability but have been prominent voices in the field of disability. Anthropological theories have influenced the public discourse on disability by focusing on cultural conceptions of disability. The cultural relativity of disability has had a profound influence on the treatment of people with disabilities over time (Cervinkova, 1996; Klotz, 2003).

DEFINING DISABILITY

The Americans with Disabilities Act (ADA, 1990) describes disability as "physical or mental impairment, which substantially limits one or more … major life activities" (ADA 1990). Others simply define disability as the "loss or abnormality of psychological, physiological, or anatomical structure or function" (Susman, 1994, p. 15). There are many definitions of disability and

impairment that are sometimes overlapping and sometimes distinct. Some researchers are careful to distinguish the differences between impairment and disability:

> Individuals are impaired if they experience (or are perceived by others to experience) physiological or behavioral statuses or processes which are socially identified as problems, illnesses, conditions, disorders syndromes, or other similarly negatively valued differences, distinctions, or characteristics which might have an ethnomedical diagnostic category or label.... Disability exists when people experience discrimination on the basis of perceived functional limitations. (Kasnitz & Shuttleworth 2001, p. 2)

HISTORY OF ANTHROPOLOGICAL CONTRIBUTIONS TO DISABILITY STUDIES

Anthropology is relatively new to disability studies, with a few pioneering works forming the foundation for a growing field of current study. Anthropologists have contributed to the understanding of disability in a social and cultural context, through the use of ethnographic, phenomenological, and cross-cultural methods (McDermott, 1995; Senghas, 2002).

One of the first anthropological studies of disability was conducted by Ruth Benedict, a pioneer in the field of anthropology, who published a seminal study of cross-cultural conceptions of epilepsy (Benedict, 1934). This was the first major anthropological study of disability, and since the 1930s, a cultural framework has been central to the anthropological study of disability. In the 1940s, research in this area was scarce, as anthropology turned its attention to other cultures. Jane and Lucien Hanks (1948) published a cross-cultural study that focused on the social factors that influence the status of people with disabilities in a variety of cultures, including Native American, Asian, Pacific, and African populations.

During the 1950s, Margaret Mead, a student of Ruth Benedict's and influential anthropologist in her own right, made public comments that included people with disabilities within the realm of "normal" Americans. She argued that the study of American national character had to include all types of Americans (Mead, 1953). This was the first significant proposition that people with disabilities need to be included in anthropological inquiry to fully understand human nature.

The introduction of the disability rights movement and the independent living model in the 1960s and 1970s brought disability to the forefront of national attention and sparked the interest of medical and cultural anthropologists (Edgerton, 1967, 1984, 1993). Cervinkova (1996) explained that anthropology's social conceptualization of disability formed a theoretical

support for the independent living model because it provided social models of disability. Sociologist Erving Goffman's (1963) concept of stigma provided support for the next phase of the anthropological study of disability.

Anthropologist Robert Edgerton (1967) was the first to explore mental retardation from an anthropological perspective. Edgerton's (1967, 1984, 1993) lifetime of work in this area contributed significantly to anthropological interest in mental retardation and disability. By the 1980s, Edgerton noted that "anthropology has begun to tiptoe its way toward involvement in the study of mental retardation" and he encouraged others to apply anthropological concepts to the field of disability studies (Edgerton, 1984; Klotz, 2003).

Prior to the 1970s, disability was considered a "private problem of unfortunate families and their individual members," but the decade brought changes to the developing field of disability (Frank, 1986b, p. 43). Disability was still a marginalized field of study for anthropologists in the mid-1970s, when Frank brought "phenomonelogical perspective to anthropological study" of a "congenital amputee" (Frank, 1984, 1986a, 1986b; Shuttleworth, 2001, 2004). Previously, anthropological study had focused on etic accounts of behavior. Etic research uses culturally neutral description by an outside observer in terms that can be applied across cultures or social environments.

In contrast, Frank's emic approach attempts to present the subject of research in a way that closely approximates the perspective of the subject. Emic research is culturally specific and describes human behavior in the context of the social environment. Frank accomplished this through developing long-term relationships between researcher and subject and through a deeper level of self-disclosure by the researcher than would be appropriate in etic research. Frank's work provided a detailed description of the lived experience of an American woman named Diane DeVries, who had been born without arms and legs. At the time, the field of anthropology was interested solely in researching the experiences of "other" cultures, and any American subject was considered to be not "different enough" to qualify as an appropriate study for anthropologists (Frank, 1986b). Frank's decades of ethnographic interviewing with Diane DeVries and her tireless presentation of this material broadened the scope of anthropology's interest to include people with disabilities.

Anthropological inquiry in disability blossomed during the 1980s. Joan Ablon emerged as a major scholar in the field and influenced future generations of anthropologists interested in disability (Ablon, 1984, 1988, 1992, 1999). Louise Duvall, a medical anthropologist, began the *Disability & Culture* newsletter, which became a main source for anthropological and other social science theory about disability. Sue Estroff (1981) explored the experiences of people with psychiatric issues from an ethnographic perspective, broadening anthropology's interest in mental health and psychiatric illness. Nora Ellen Groce (1985) published her findings about the deaf and hearing individuals on Martha's Vineyard, where hereditary deafness occurred with

such frequency that it was not considered a disability (and nearly everyone spoke sign language). The International 2001 of Disabled Persons was dedicated in 1981, followed by the Decade of Disabled Persons spanning from 1983 to 1992, but Ingstad (1995) stated that "one can hardly note any revolutionary changes in the life situation of disabled people" as a result of demarcating that particular decade (p. 246).

In the 1990s, interest in the anthropological study of disability continued to grow. The story of the "Elephant Man" captivated both anthropologists and the general public. Books, articles, and films about Joseph Merrick abounded, describing and analyzing his experiences with a condition that caused extreme and progressive facial and bodily deformity (Ablon, 1995; Montagu, 1995).

Another life history fueled anthropological interest in disability studies. Robert Murphy, an anthropologist who had accumulated a lifetime of work on native cultures of Africa and Asia, slowly became paralyzed over a decade owing to a tumor on his spine. He spent the last years of his life researching disability. His book about his experience of disability, *The Body Silent*, has become a classic text for both disability studies and anthropology (Murphy, 1990). This publication increased anthropologists' interest in disability, and it provided increased legitimacy for anthropologists to enter the field of disability studies.

In the mid-1990s, Ingstad & Whyte (1995) edited a significant book on the sociocultural aspects of disability, titled *Disability and Culture.* It called for the field of anthropology to broaden its study of disability to include an emphasis on personhood and phenomenological approaches rather than traditional medical anthropology techniques. This important volume was cited by almost every article and book about anthropology and disability since 1995.

Today, one of the most prominent voices in anthropological discourse on disability is Devva Kasnitz, sometimes working in collaboration with Russell Shuttleworth (Kasnitz, 2001; Shuttleworth, 2001; Shuttleworth, & Kasnitz, 2004). Kasnitz has been a strong advocate for anthropology to engage more fully with disability studies and has argued for increased legitimacy for the contributions of anthropologists with disabilities. Shuttleworth's work has focused on disability and sexuality and on social constructions of disability. Together and individually, these researchers have revolutionized the discussion of disability and have brought disability to the center of anthropological discourse.

CONTRIBUTIONS FROM MEDICAL ANTHROPOLOGY

Medical anthropology is among the main contributors to the understanding of disability and impairment. Because medical anthropologists were some

of the first to approach the subject of disability, medical anthropology has contributed significantly to the definition of terms and has provided some of the foundations for the field's discussion of disability (Littlewood, 2006). However, the major journal of medical anthropology, *Medical Anthropology Quarterly*, made little mention of disability (1987–2006) until well into the 1990s (Shuttleworth, 2004).

Medical anthropology's perspective on disability has a "therapeutic theme," utilizing medical conceptions of disease and illness to explain disability (Littlewood, 2006). This medical model implies a "mandate" to "cure" people with disabilities (Scheer, 1988; Shuttleworth & Kasnitz, 2004). Medical anthropology has contributed much to the understanding of disability; however the medical model can limit the discussion. Shuttleworth (2004) notes that in the absence of a "phenomenology of illness, therapeutic treatment, and/or a culture's ethnomedical system, many medical anthropologists choose not to study disability/difference" (p. 368). Shuttleworth encourages the field to broaden and deepen its understanding of disability.

Many important contributions derived from medical anthropology also include aspects of social or cultural anthropology. The earliest medical anthropological studies of disability presented the perceptions of different cultures regarding certain disabilities, such as epilepsy or deafness (Ablon, 1981; Benedict, 1934; Littlewood, 2006; Rao, 2006). Ablon's pioneering ethnographic approach to the study of disability, specifically working with stigmatized populations, helped to move medical anthropology from a disease framework of disability to an ethnographic focus (Shuttleworth & Kasnitz, 2004; Shuttleworth, 2001). This broadened the scope of disability and impairment studies within anthropology and allowed the voices of people with disabilities and their lived experiences to contribute to anthropological theorizing on disability (Shuttleworth & Kasnitz, 2004).

Because of the ethnographic nature of Ablon's research, the focus of disability study shifted to the social exclusions and limitations that come "into play as a result of bodily differences" (Shuttleworth & Kasnitz. 2004, p. 142). Ablon was one of the first anthropologists to focus on the social reactions of the community to people with disabilities as the disabling force, rather than implicating the bodily differences as the true source of disability. This changed the focus from the human behavior of people with disabilities to the social environment of the population at large.

STIGMA, DEVIANCE, AND LIMINALITY

Stigma and deviance are essential concepts from social and cultural anthropology that can be applied to disability (Devlieger, 1999; Rosing, 1999). Deviance may be defined as straying from the "prevalent or valued norms" in a way that the society perceives as "negatively deviant" (Becker, 1983;

Susman, 1994, p. 16). Disabled bodies have traditionally been labeled deviant because they stray from the norm and invoke stigma through this deviance (Stiker, 1999). Many anthropological inquiries, including pioneering studies in disability and the *Encyclopedia of Medical Anthropology* have utilized Goffman's concept of stigma: "a discrediting attribute, and undesired differentness from social expectation" (Ablon, 1981, 1984, 1988, 1992, 1995; Edgerton, 1967, 1993; Gleeson, 1997; Goffman, 1963; Ingstad, 1995; Shuttleworth, 2004; Shuttleworth & Kasnitz, 2004; Stiker, 1999). See Figure 1 for a depiction of the concepts of deviance, stigma, and liminality.

Others describe stigma as the "evocation of adverse responses" (Susman, 1994, p. 15). Disabled anthropologist Robert Murphy described people with disabilities as "subverters of the American Ideal" because their bodies or circumstances restrict their ability to achieve "independence, self-reliance, and personal autonomy," which he describes as quintessential American values (Murphy, 1990). Murphy focused on the perceived deviance of disabled bodies that can lead to stigma and marginalization, while criticizing Goffman's more simplified approach to stigma, deviance, and disability (Goffman, 1963; Murphy, 1990).

Social and cultural anthropologists have applied the theories of deviance and stigma to the study of disability, incorporating the concept of "the other" (Cervinkova, 1996; McGrane, 1989). Deviance and stigma may be associated with "nonnormative bodies" or behaviors and may define the
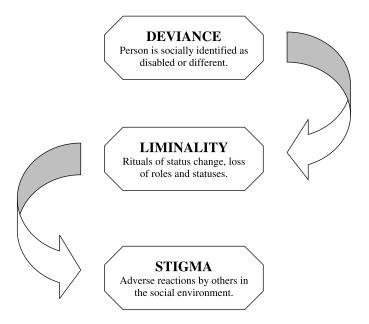

FIGURE 1 Conceptual map of anthropological contributions to disability.

social experiences of people with disabilities (Shuttleworth & Kasnitz, 2004, p. 148).

The terms used by the disabled community to describe "non-disabled" people include "TAB or MAB (temporarily or momentarily able-bodied)" (Zola, 1993). Members of a society may fear and even resent people with disabilities based on a fear of becoming disabled themselves. This fear and resentment can lead to stigma, marginalization, and oppression of people with disabilities (Cervinkova, 1996; Goffman, 1963; Rosing, 1999). The stigma associated with disability stems from the knowledge that anyone can become disabled at any time (McDermott, 1995; Zola, 1993).

Social and cultural anthropologists have contributed significantly to ethnographic inquiry and social constructions of disability and impairment (Devlieger, 1999). The concept of liminality in anthropology refers to transitions between social roles and statuses and the ambiguity that may be associated with role or status change. Liminality refers to a ritual or rite of passage in which there is a change of social status (Devlieger, 1999; Ingstad, 1995; Murphy, 1990; Murphy, Scheer, Murphy, & Mack, 1988; Stiker, 1999; Turner, 1967). Anthropologists studying disability often invoke theories of liminality to explain the stigma applied to people who become disabled (Devlieger, 1999; Ingstad, 1995; Stiker, 1999). Murphy (1990) described his own process of becoming gradually paralyzed as a series of liminality rituals, stripping his social statuses as he became more disabled in the eyes of the culture at large. The liminal state is described as a time of transition, characterized by ambiguity (Ingstad, 1995; Murphy, 1990; Turner, 1967). People with disabilities may experience an extended or even perpetual state of liminality because of role confusion and a lack of acceptance by others (Murphy et al., 1988). Many do not accept the liminal identity ascribed to them by society and may create their own culture of disability to support and inform their experiences (Ingstad, 1995).

DISABILITY AS CULTURE

Some theorists assert that the community of people with disabilities may be considered a culture or subculture, or that certain groups of disabled people may have their own culture (such as Deaf Culture) (Cervinkova, 1996; Fjord, 1996; Frank, 1986b; Stiker, 1999). Approximately 74% of Americans with disabilities report a common cultural identity, whereas 45% consider themselves to be part of a minority group (Nagler, 1993). Some anthropologists have called for public recognition of the disabled as a minority group, whereas others caution against lumping such a diverse group of people into a single minority category (Biklin, 1988; Gleeson, 1997; Susman, 1994; Zola, 1993).

One commonly used definition of culture states that a culture includes a common language, a historical lineage, evidence of a cohesive social

community, political solidarity, acculturation at an early age, generational or genetic links, and pride and identity in segregation from others (Peters, 2000). Many communities of people with disabilities meet these criteria, particularly deaf individuals who identify primarily with deaf culture. In fact, the deaf community has been described as "a highly endogamous, clearly demarcated cultural community" (Ingstad, 1995, p. 17). The debate about the definition of a "disabled culture" or "culture of people with disabilities" continues to rage, with researchers, theorists, and people with disabilities making contributions to the evolving definitions of culture and identity.

SYNTHESIS AND KEY CONCEPTS

The field of anthropology has made significant contributions to the understanding of disability. Theories from medical, social, and cultural anthropology have broadened public and academic discourse on disability. The social conception of disability, drawn from anthropology and sociology, provided the Independent Living movement with a theoretical support that increased the movement's legitimacy and helped to broadcast its message (Cervinkova, 1996; Goffman, 1963). Anthropology and sociology have provided theoretical and empirical support for the assertion that disability may be considered a cultural demarcation and that people with disabilities may identify with a different culture than the general population in a society.

Anthropologists have determined that the disability is socially constructed: It depends very little on the degree of functional loss or impairment; rather it is defined by societal standards for normative bodies, behaviors, and role fulfillment (Armstrong & Maureen, 1996; Holzer, 1999; Ingstad & Whyte, 1995; Susman, 1994, p. 15). As a result, disability is viewed less as a limitation or dysfunction than as the "perceptions and prejudices of an able-bodied majority" that restrict the independence of people with disabilities (Cervinkova, 1996). Some anthropologists have even gone so far as to claim that disability can be considered nothing more than a cultural fabrication, citing cross-cultural studies of disability and impairment to support their assertion (Holzer, Vreede, and Weigt, 1999; McDermott & Herve, 1995).

The significance of disability is culturally produced, and different cultures conceive of disability in diverse ways (Devlieger, 1995, 1999; Holzer et al., 1999; Klotz, 2003; Littlewood, 2006; Peters, 2000; Whyte, 1995). For example, the Hindu concept of karma explains disability within some cultures, while Australian aboriginals may attribute disability to social or ritual transgressions. Some African cultures relate disability to witchcraft and curses, whereas Christians may cite sin as the cause of disability, and Muslims relate disability to fate or the will of Allah (Armstrong & Fitzgerald, 1996). Religious teachings, laws, customs, and "media portrayals also reflect, define, or perpetuate" how people approach disability (Peters, 2000; Susman, 1994, p. 18).

EMERGING RESEARCH QUESTIONS AND
AREAS FOR EXPANSION

There is a need to continue building on the foundation of social and cultural constructions of disability. The concepts of stigma, deviance, and liminality can be applied to specific disabilities by focusing on the lived experience of people with disabilities. An ethnographic lens continues to provide a valuable perspective for understanding disability, especially the experiences of people who are different from the researcher.

Though the perspective of "the other" is important and has provided some insights to nondisabled anthropologists, it is essential to incorporate the work of disabled anthropologists who have been marginalized and minimized in the field (Murphy, 1990; Stiker, 1999). Murphy noted that disabled researchers may have particular strengths in working with disabled subjects, and the field of anthropology needs to make use of these strengths to fully explore the phenomenological experience of disability (Ingstad, 1995). Moving forward, the field needs to incorporate and prioritize the voices of those people with disabilities.

Each area of disability could benefit from increased attention by anthropologists. Though physical disability has received most of the attention, these studies have focused primarily on very particular types of physical disability, such as dwarfism, deafness, and epilepsy (Ablon, 1984, 1988; Groce, 1985; Whyte, 1995). Other types of disability should be more thoroughly investigated, including mental illness, emotional disabilities, learning disabilities, and mental retardation (Edgerton, 1984; Littlewood, 2006). There are many areas of disability that would benefit from anthropological insight.

The anthropological perspective is important to the study of human behavior and the social environment. The use of emic and etic perspectives by anthropologists has provided valuable information about human behavior from a variety of standpoints. The anthropological concepts of liminality and status-change rituals are highly relevant to the study of the social environment. Concepts such as stigma and deviance are highly relevant to the study of human behavior and the social environment and already feature prominently in many curriculums in human behavior in the social environment. The application of anthropological concepts to the study of disability within the realm of human behavior and the social environment is an emerging area of study.

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