
Disability/Difference

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INTRODUCTION

This entry has three primary aims: (1) to provide a brief overview of the kinds of bodily and behavioral differences perceived as anomalous in a range of societies and the various social responses to these differences; (2) to review and critique research and theory in the anthropology of impairment–disability; and (3) to suggest several conceptual advancements that would move this area of study forward.

CROSS-CULTURAL REVIEW OF RESPONSES TO BODILY AND BEHAVIORAL DIFFERENCES

As a broad inclusive category, and from a strict constructionist perspective, disability exists only in locally specific relation to Western European notions of medicalization, employment, and welfare (Groce, 1999; Whyte & Ingstad, 1995). Yet, some range of physical and behavioral

differences are recognized in all societies and there are often social consequences that follow from this recognition. While it is of paramount importance to elucidate local contexts, knowledge, and responses in the study of these differences (Devlieger, 1999; Groce, 1999; [Ingstad, 1999b](#)), anthropology is a comparative discipline and in their research on impairment-disability cross-culturally, anthropologists implicitly or explicitly make comparisons between the local worlds of their informants and their own usually Western European or North American societies. This can prove difficult given the variation in cultural conceptualizations of bodily and behavioral differences.

This brief review uses Mary Douglas's (1966) notion of anomaly, "matter out of place," as a baseline concept to orient a comparative approach. This notion has been widely acknowledged by many anthropologists and cultural theorists as providing a starting point from which to begin to understand the cultural meanings and implications of these kind of differences (see, e.g., Murphy, 1987; Shakespeare, 1994; Shuttleworth, 2000b; Stiker, 1999a, 1999b; Thompson, 1997; [Whyte, 1995b](#)). Of a different order than liminality, "matter out of place is a culturally constituted perception" that does not fit within recognized cultural categories "and not a phase in a (ritual) process" (Shuttleworth, 2000b, p. 80). Douglas views anomaly as inherently threatening to the social order. Devlieger (1999) refers to disability as an interstitial category, which adds a structural component to the concept of liminality. This section considers the kinds of bodily and behavioral differences perceived as anomalous in a range of societies and the various social responses to these differences. The question of how to define disability-related terminology will be explicitly addressed in a later section, but for now it is enough to mention that much of the research reported on below does not often sustain an effort to analytically distinguish between anomalous bodily and behavioral differences from impairment and disability.

In terms of body and behavior, any out of the ordinary manifestation may be perceived as anomalous. This does not necessarily mean that people exhibiting certain recognized differences will either be stigmatized or viewed as sacred (Rosing, 1999; see also Douglas, 1966). [Ingstad \(1999a\)](#) makes the observation that in many societies "physical and mental impairment is not necessarily what determines the status and inclusion of a person.... More important are family and kinship ties, competence in doing useful tasks for the good of the household, and

the ability to behave in a socially acceptable manner" (p. 757). For example, Marshall (1996) notes that among societies of the Caroline Islands in Micronesia "individuals impaired from birth defects, accidents, or diseases are not necessarily considered disabled unless the impairment is coupled with an inability to speak and/or hear; that is with an inability to manipulate culture and to participate in the social life of the community" (p. 254). These Micronesian societies appear not to stigmatize people with many kinds of physical impairments, as long as one is personally and culturally competent.

Much depends on the interplay of beliefs, social expectations, and economic imperatives of the particular society as to whether some bodily or behavioral anomaly will be considered a disability (Groce, 1999). For example, in China today the ability to be active and mobile outside the home in terms of public life and also in one's livelihood is highly prized. Combined with ideas about national development and mobility and the Confucian emphasis that transmutes bodily imperfection into social meaning, men who have difficulty walking experience stigma and discrimination (Kohrman, 2000, [n.d.](#)). Here cultural beliefs, social and gender expectations, and also economics conspire and contribute to the creation of an identity based on a negatively perceived bodily difference. In some less modernized societies the situation may be entirely different, as alternative tasks and roles are found that contribute to the group. As Scheer and Groce (1988) state, "although specific occupations or trades might be closed to a disabled person because of his or her specific impairment (such as hunting to a mobility impaired man), there seems no single role or group of roles to which most disabled adults are limited" (p. 29).

Negative social consequences can range from mild stigmatization through infanticide. For example, among the Shona of Zimbabwe, Burck (1999) reports that children who get their upper teeth first are considered seriously disabled and this has lifelong consequences. A 1980 survey on leprosy in Nepal found that a majority of persons would separate family members who got leprosy, and a third said they would put them out of the village. Ten years later in 1990, there was little change in expectations (Hyland, 2000). Turmasani (1999a, 1999b) reports widespread negative social attitudes toward physically disabled people in Jordan resulting in charity, the attribution of cognitive impairment, and an asexuality (not unlike some of the attitudes and responses in the United States). The birth of twins constitutes a social disgrace among the

Punan Bah and one of them is usually given away or withers away (Nicolaisen, 1995). Similar data exist from other societies including those in the past. Dasen (1993), for example, states that in Greco-Roman Egypt protection against evil by oracles was sought in the case of multiple births. The extreme exclusionary practice of infanticide occurs in some societies (see, e.g., Devlieger, 2000; Scheer & Groce, 1988). Although not as widespread as previously thought, neglect of impaired infants is usually not included as infanticide (Scheer & Groce, 1988; see also Scheper-Hughes, 1990, 1992). The most common justification across cultures for infanticide, as Scheer and Groce (1988) state, is the "belief in the linkage between evil spirits and/or parental misconduct" (p. 28). Yet, as Talle (1995) notes, integration is not necessarily always the answer. Among the Maasai, children with an impairment are treated the same as other children, given the same food, ritual blessings, ceremonial procedures, and level of support. However, the lack of special treatment often results in early death.

On the other hand, some physical and behavioral differences in various societies can be accorded positive significance of a sacred or trans-personal character. For example, Rosing (1999) maintains that among the Quecha-speaking people in the Kallawaya region of the Bolivian Andes, they do not necessarily perceive people who are blind or with crippled hands, among other differences, as disabled. She notes that "there is initially a culturally defined, positively evaluated area of meaning which can be seen as a cultural resource" (p. 38). If other personal, social, internal, and external resources are met, such as reciprocity and exchange, and personal representation by some personal object is fulfilled, then "disabling characteristics" may be perceived not as illness, impairment, and disability but of vocation, sometimes of a trans-personal concept. One example Rosing provides is of a blind man who is ascribed a type of trans-personal vision, which allows him to see the unseen.

Many bodily and behavioral differences recognized as anomalous in other societies, such as the birth of twins and upper teeth coming in first, are not especially important to societies influenced by Western European orientations. In fact, this points to a significant difference noted by some cross-cultural researchers: lack of perceived function seems to be the core negative meaning that characterizes an impairment-disability in the latter societies (Burck, 1999). The extreme version of this, of course, is the biomedical model of impairment-disability. In many

societies, however, other ethnophysiological or ethnopyschological concepts or indices may be highlighted instead of or in addition to function. For example, among the Shona, "dryness of the affected part" (presumably) within their humoral system, is the essential factor in determining disability (Burck, 1999, p. 203). In addition, in many non-Western societies, interpreting fault often takes precedence over assigning blame to the individual or wanting to improve the individual's condition or situation (Devlieger, 1995). As Devlieger notes, "The idea of rehabilitation as a continuous effort of improving and accommodating the living conditions of persons with disabilities is basically a Western idea that is foreign to Songye thought" (p. 95).

All societies recognize and respond to cognitive differences and erratic behavior. However, Nicolaisen (1995) says the Punan Bah do not hold the mentally impaired responsible for their situation (see also Marshall, 1996). Epilepsy and madness are caused by non-human spirits who invade or partly take over the body, relegating the soul of the body to a secondary position. Effort is made by families to cure madness by way of spirit mediums. Persons so affected are regarded as dangerous only if violent. For the most part, effort is made to include them as part of regular social relationships. On the other hand, for the Hubeer stupidity and madness are viewed as similar to infertility and death and the mentally impaired are often treated with abuse outside of their family (Helander, 1995, p. 89). Talle (1995) states that among the Kenya Maasai mentally retarded or mad persons are regarded not as disabled in a physical sense but as "abnormal" ("fool"). Nicolaisen (1995) echoes an observation made by many cross-cultural researchers that some forms of severe cognitive difference such as severe forms of mental retardation, "... among the Punan Bah. I suspect that children born with such impairments 'wither away' ... or die at an early age" (p. 44).

Examining a particular social context within a society can further reveal that those with certain physical and behavioral differences may encounter restricted access. Anthropologists often note in their studies of impairment-disability in other societies that physical and/or cognitive impairment does not necessarily determine status and exclusion, that family and kinship ties are more important (see, e.g., Ingstad, 1999). What are we then to make of the fact that in the context of sexual and/or marriage negotiation and family formation, it has also paradoxically been observed that people with bodily

and behavioral differences often encounter difficulties in a range of societies (see, e.g., Ablon, 1984, 1995, 1999; Devlieger, 1995; Fassin, 1991; Guldin, 1999, 2000; Kohrman, 2000, n.d.; Nicolaisen, 1995; Sentumbwe, 1995; Shuttleworth, 2000a, 2000b)? This is not to say that impaired people are always excluded from these institutions and activities (see, e.g., Guldin, 1999, 2000; Sentumbwe, 1995; Shakespeare, Gillespie-Sells, & Davies, 1996; Shuttleworth, 2000b; Wolf & Dukepoo, 1969). However, impairment or some other ethnophysiological or ethnopsychological indicator interacting with differences of gender, class, etc. will often be significant in determining negative cultural beliefs, social expectations, and responses regarding sexual and/or marriage negotiation and family formation for people with certain bodily and behavioral differences.

Joan Ablon (1996), for example, exploring the differential access to intimacy and sexual experiences for men and women with neurofibromatosis found that two thirds of the women she interviewed were married, as opposed to only one third of the men. The single men in her sample were much less likely to have had sexual experiences than the women. Ablon notes the persistence of women in finding a partner. She hypothesizes that they continue strategizing to connect with a man because in U.S. society women are socialized to be interpersonal communicators. However, the lack of achievement by many of the men, due to early learning disabilities and social failures, negatively impacts their gender identity, which significantly contributes to their social withdrawal. Nayinda Sentumbwe working in Uganda (Sentumbwe, 1995), provides another instance: he found that cultural beliefs that blindness is incapacitating contributed to the fact that sighted men will have sexual relations with blind women and/or keep them as mistresses but rarely marry them because of their desire for a domestically competent wife. This dynamic was missing for blind Ugandan men who would often marry sighted women. Matthew Kohrman's (2000) research on disabled men in China provides a somewhat different example: for men with mobility impairments and their families, during negotiations for a wife, they must continually negotiate downward in terms of the social position of their prospective partner, which indicates to them their diminished social value and disabled identity.

What is interesting to note is that, as alluded to above, exclusion from the primary institutions of marriage and/or family or from effectively negotiating

sexual intimacy with others often occurs in many societies for people with certain physical and behavioral differences, despite their being accorded other aspects of personhood. One must question anthropological observers who report that disabled people are well integrated into a society and yet cannot negotiate sex, marry, and/or form a family. Despite the importance of detailed views of how well particular sociocultural contexts do or do not integrate people with culturally recognized physical/behavioral differences, we need this kind of in-depth information for multiple contexts within a society and across many societies in order to perform effective cross-cultural analyses.

REVIEW AND CRITIQUE OF THEORY AND RESEARCH

While some early anthropologists remarked on the social position of disabled people cross-culturally (see the discussion in Hanks & Hanks, 1948), it was not until the 1960s with the theoretical impetus of Goffman's (1963) elaboration of the stigma concept and Edgerton's (1993) research on people with "mental retardation" that a focused interest in the systematic study of the sociocultural aspects of impairment and disability began to develop. The seminal work on disability conducted from the 1970s up through the late 1980s by cross-cultural researchers was notable in orienting this area of study in certain theoretical directions, toward stigma, liminality and, to a lesser extent phenomenology, that still hold influence (see, e.g., Ablon, 1981, 1984, 1988; Becker, 1981; Duval, 1984; Estroff, 1981; Frank, 1984, 1986, 1988; Goerd, 1984; Goldin, 1984; Groce, 1985; Gwaltney, 1970; Langness & Levine, 1986; Murphy, 1987; Scheer, 1987; Scheer & Gross, 1988; Schepers-Hughes, 1979). Empirically what strikes one about this body of work, as Whyte and Ingstad (1995) note, is that the majority is "based on research in North America" (p. 4). Additionally, except for the review of the research literature offered by Scheer and Groce (1988), all of this work focuses on single impairments with no attempts at cross-impairment analysis within a society and between societies (Kasnitz & Shuttleworth, 1999, 2001b).

More recently, anthropologists and other cross-cultural researchers have investigated impairment-disability using various perspectives in a wide range of

societies including, among others, those in Africa (Devlieger, 1995; Fassin, 1991; Helander, 1995; Ingstad, 1995; Kaplan-Myrth, 2001; Sentumbwe, 1995; Talle, 1995; Whyte, [1995a]), South America (Block, 1997, n.d.; Bruun, 1995; Rosing, 1999), Native Americans (Pengra & Godfrey, 2001; Schact, 2001), Borneo (Nicolaisen, 1995), China (Kohrman, 2000, [n.d.]), India (Ghai, 2002), Nepal (Hyland, 2000), Micronesia (Marshall, 1996), Mexico (Holzer, 1999), Southeast Asia (French, 1994; Predaswat, 1992), the Middle East (Colligan, 1994, 2001; Dshen, 1992; Turmusani, 1999a, 1999b), Western Europe (Corker & Davis, n.d.; Davis, 1998; Hubert, [2000a]; Monks & Frankenberg, 1995; Raji & Hollins, 2000), and North America (Ablon, 1995, 1996, 1999; Angrosino, 1992, 1994, 1998; Eames & Eames, 1997; Frank, 1984; Gold, [1994], n.d.; Kaufert, 2001; Landsman, 1997, [n.d.]; Luborsky, 1994; Pawlowski, 2001; Peace, 2001; Preston, 1994, 1995; Scheer & Luborsky, [1991]; Shuttleworth, 1998, 2000a, 2000b, 2001a, 2001b, 2002). An important volume appeared in 1995 edited by Benedicte Ingstad and Susan Reynolds Whyte, which examines disability through the general theoretical lens of personhood (see also Bruun & Ingstad, 1990). Other edited works that have recently appeared include those by Holzer, Vreede, and Weigt (1999), which highlights the dialogue between scientific praxis and practical rehabilitation efforts, and Hubert ([2000c]), significant for including archeological perspectives as well as current ethnographic research on the issue of social exclusion of those with physical or behavioral differences. One critique of past as well as some present work is that detailed taxonomies of what are perceived to be impairments in different societies and which impairments are disabling are often not presented (however, see, e.g., Devlieger, 1995; Nicolaisen, 1995; Talle, 1995). Likewise, this body of research does not give us much of an understanding of the interactions occurring in multiple contexts/domains during everyday life for people with bodily and behavioral differences.

Until recently, much of the anthropological research on impairment-disability has been conceptualized in terms of a relatively few theoretical notions, the most notable of which are liminality and stigma. Anthropological and other cross-cultural research utilizing the concept of stigma, that is, a discrediting attribute or an undesired differentness from social expectations, have contributed significantly to understanding the sociocultural construction of certain chronic illnesses and impairments (see, e.g., Ablon, 1981, 1984, 1988, 1999;

Angrosino, 1992; Becker, 1980; Becker & Arnold, 1986; Edgerton, 1993; Gussow & Tracy, 1968, 1970; Herskovits & Mitteness, 1994; Predaswat, 1992). Goffman, however, has been criticized on several grounds including for lumping together all sources of stigma and overgeneralizing (Murphy et al., 1988; Wendell, 1996), for not being sensitive to issues of politics and empowerment (Anspach, 1979; Hahn, 1985) and for reflecting some of the cultural stereotypes and meanings of disability at the time he was writing, in the late 1950s and early 1960s (Wendell, 1996).

Goffman's critics hold him to an impossible hermeneutic demand—to step outside his historical moment and render a disability-centric analysis. Showing that “the meaning of disability is a social, therefore changeable, construction” (Susman, 1994, p. 15), he actually paved the way for today's more critical disability discourse (Shuttleworth, 2000b). Important theoretical expansions include Herskovits and Mitteness's (1994) model, which shows how the degree of stigma varies for different chronic illnesses and impairments depending on the different cultural values that are transgressed, and Shuttleworth's (2000b) model that shows how degree of stigma will vary from context to context for someone with a certain impairment as the particular social context calls for the use of some culturally defined abilities and invokes some values but not others.

Stigma, however, remains a disembodied notion in much of the above research. That stigma can often lead to internalized oppression or, conversely, to self-empowerment needs to be theoretically grounded in intersubjective processes. How do disabled people engage and contend intersubjectively with a particular form of stigmatization and other impediments to full societal participation at an embodied level of experience? Phenomenology may be able to uniquely elucidate this process. Frank's (1986) research on the life of a woman with missing limbs, Diane DeVries, was an early attempt to bring a phenomenological perspective into the anthropological study of disability. Yet, Frank's phenomenological work only focused on one disabled person's image of her body. Her later work (Frank, 1988, 2000), albeit some of it is informed by phenomenology, does not attempt to describe the process of empowerment in existential and intersubjective terms. In fact, she philosophically rejects interpreting Diane's “ultimately unnamable, lived experience” (Frank, 2000, p. 123; Shuttleworth, 2000b). However, in the last few years several attempts within

anthropology and sociology to develop phenomenological and existential-phenomenological perspectives further have been presented (see French, 1994; Hughes, 1999; Hughes & Paterson, 1997, 1999; Shuttleworth, 1998, 2000a, 2000b, 2001). For example, Paterson & Hughes (1999) outline a phenomenological perspective on impairment that draws much from the work of Leder (1990) and shows how embodied contexts of meaning are structured by non-disabled embodiment.

The symbolic anthropological study of impairment-disability has not moved much beyond a focus on the ritual notion of liminality. In a much-cited article, partially intended to move beyond what they perceived to be the inadequacies of the stigma concept and the language of deviance, Murphy et al. (1988) propose that the concept of liminality could also apply to the social response to disabled people in American society (Goldin & Scheer, 1995; Murphy et al., 1988; see also Willett & Deegan, 2001)). Disabled people have indeed often been isolated, made invisible, seen as contaminated, avoided, without status, and economically marginalized. These and other responses are reminiscent of the social responses to initiates who undergo the liminal phase of many rites of passage (Turner, 1967). Thus, Murphy et al. argue that, "disability is not a thing, it is a juncture within a process—an arrestment in life history that is dramatized in a rite of passage frozen in its liminal stage (1988, 241).

However, Murphy and his associates err by trying to force the processual notion of liminality onto the lived experience of disability in general. The problem is that they draw almost entirely from the experience of persons with late-onset impairments. Extrapolating from the experience of this population, Murphy et al. (1988) suggest that "the physical laws of the disabled are better seen as 'losses,' rather than as 'deficiencies,' for most of the sightless once saw and most of the crippled once ran" (p. 241). However, people with early-onset impairments do not experience the first phase of the proposed liminal model, that is, separation from "normal bodies." Therefore, their physical laws cannot be considered "losses" in any sense of the term (Kasnitz & Shuttleworth, 1999; Shuttleworth, 2000b).

As mentioned earlier in this entry, a more consistent model, that would not only apply to disability in the U.S. context but also cross-culturally, is that certain bodily and behavioral differences are perceived as anomalous or as "matter out of place" (Douglas, 1966). Matter out of place falls in between cultural categories and is thus

interstructural, or interstitial in Devlieger's (1999) scheme. This accords more with the social and lived experience of people with early-onset impairments, since they do not experience the prior phase of being in place, which is necessary in a strict liminal model (Kasnitz & Shuttleworth, 1999; Shuttleworth, 2000b).

While there has been some attention to metaphor in ethnographic research with disabled people (see, e.g., Angrosino, 1992; Duval, 1984; Phillips, 1990), this work has been intermittent (Shuttleworth, 2000b). Stiker's (1999a, 1999b) historical semiotic approach perhaps represents the most ambitious attempt to move the symbolic study of disability forward. Stiker asks: What is the semiosis within a society that integrates and/or excludes persons exhibiting particular bodily or behavioral differences? How a society views the biological integrity of the species (their ethnophysiology) will be a contributing factor in its forms of integration or exclusion. Stiker, reviewing biblical and historical texts, situates his analysis of the meaning of disability in the West on several isotopies—biological, ethical, religious, social, and medical—with some isotopies moving to the foreground in certain historical epochs and some receding more into the background or merging with other isotopies. Depending on the interplay of these levels of meaning and imaginative investment in the normal during a particular historical epoch, the West has moved between the poles of integration and exclusion of disabled people. For example, in the biblical system disability is primarily a question of biological integrity, which the ethical-religious perspective can situate but not necessarily integrate or treat. Exclusion exists centrally in the prohibition of people with certain impairments from participating in religious rituals (Stiker, 1999a). Transposing his semiotic method of textual analysis and interpretation of disability to societies beyond those in the West has so far not been systematically attempted, albeit Devlieger (1998) renders a social semiotic analysis of representations of physical disability in colonial Zimbabwe through the movie *Pitaniko*, the Film of Cyrene.

Some anthropologists have attempted to conceptualize and theorize about disability in general, often across cultures (see, e.g., Luborsky, 1994; Murphy et al., 1988; Scheer & Groce, 1988). These attempts, as well as many disability ethnographies themselves, often overlook important understudied variables such as age at onset, time since onset, course, level of pain, visibility, "hideability," predictability, availability of accommodations,

and social acceptability of impairments (Kasnitz & Shuttleworth, 1999). Another significant problem with some of these attempts is that focusing on people with a mature age at onset of impairment in their empirical examples, they attempt generalize to early-onset impairments without providing any extended analysis that their models fit this very different population. Murphy et al. (1988) are not the only culprits. Luborsky (1994), using a model of disablement developed by Verbrugge and Jette (1993), implicitly makes this generalization when reporting on a sample of post-polio, middle-aged, and elderly people whose conditions deteriorated after years of relative stability. Luborsky (1994) talks about disability as "loss" and "erosion of full adult personhood." Collapsing early- and late-onset impairments, those that worsen and improve and otherwise change or remain stable obscures the very different social and experiential dynamics that exist for people with different disability trajectories and devalues the experience of persons with early-onset impairments (Kasnitz & Shuttleworth, 1999). A more recent methodology for cross-cultural research proposed by Vreede (1999), one which relates activities of daily living (ADLs) to physical/mental functions and structures (ODLs) that are motivated by personal/social purposes (IDLs), seems promising.

Susan Whyte (1995b) advocates for the use of innovative new theoretical approaches to broaden the anthropology of disability, most notably the cultural-historical approach of scholars such as Stiker (1999a, 1999b) and Foucault (1973); a symbolic approach in the line of Douglas (1996); Kleinman and Kleinman's (1991) phenomenological approach to suffering, among other points of view. While not forsaking medical anthropology's more traditional ethnographic focus on cause and cure, she and also Ingstad (Whyte & Ingstad, 1995) generally emphasize the theme of personhood in their work. Whyte's call for an eclectic theoretical mix is slowly being taken up by anthropology—reader response theory, semiotics, Foucaultian analyses, existential-phenomenological perspectives and a radical concern for reflexivity, dialogics, insider analyses, and capturing what it is like to be impaired-disabled in divergent societies are current examples of theoretical perspectives and methodological approaches being utilized (see, e.g., Angrosino, 1992, 1998; Colligan, 1994, 2001; Corker & Davis, [n.d.](#); Davis, 1998, 2000; Devlieger, 1998; Duval, 1994; Gold, 1994; Kasnitz, 1993; Kohrman, 2000, [n.d.](#); Landsman, 1997, [n.d.](#); Preston, 1994, 1995; Raphael, Salovesh, & Laclave,

2001; Shuttleworth, 1998, 2000a, 2000b, 2001a, 2002). However, there are many perspectives currently circulating in sociocultural theory that are not yet being utilized in the anthropology of impairment-disability.

Those anthropologists utilizing innovative new perspectives are necessarily conversant with the current theoretical ferment in disability studies, which has moved well beyond its social movement beginnings and is making significant strides in conceptualizing the impairment-disability experience. Disability studies theory is expanding from an initial focus on independent living and social models to sophisticated phenomenological and post-modern conceptualizations of impairment and disability including notions that decenter the non-disabled subject and subvert normative societal conceptions of physical/behavioral difference (see especially [Allan, 1996](#); Corker, 1998a, 1998b, 1999; Corker & Shakespeare, 2002; Davis, 1995; Hughes, 1999, 2000; Hughes & Paterson, 1997, 1999; Linton, 1998; Thompson, 1997). Disability studies researchers are also increasingly venturing abroad to study the meanings of disability and disabled people's experience in diverse societies and seeing if the models developed in disability studies are applicable or not cross-culturally (see, e.g., Ghai, 2002; Stone, 1997, 1999; Valentine, 2002).

NEW DIRECTIONS IN THE ANTHROPOLOGY OF IMPAIRMENT-DISABILITY

Defining the Terms as Heuristic Notions of Negative Meaning and Oppression

In the cross-cultural study of other groups deemed "vulnerable" to oppression, such as women, ethnic/racial minorities, sexual minorities, the working class, and the elderly, subtle constructionist analyses have emerged in a variety of local contexts that have shown the complex constitution of social personhood and subjectivity and the asymmetrical relations of power that can sometimes result in their subordination in certain socio-cultural contexts (see, e.g., Bourdieu, 1984; Kondo, 1990; Weston, 1991; Willis, 1977). Yet, in past anthropological work on impairment-disability there has been minimal analysis of relations of power. In fact, many

anthropologists currently studying impairment-disability subscribe to a radical relativistic approach and a weak view of oppression that can sometimes diminish the significance of certain problematic cultural responses to people with bodily and behavioral differences. And while it is important to note some of the positive cultural responses to bodily and behavioral differences and to provide a holistic picture of a society's understanding and response to these kind of differences, recognizing and critiquing social exclusions and oppressive social relations against impaired people is also paramount.

An example of the downplaying of a problematic cultural response to differences is provided by Nicolaisen (1995), who notes the fact that among the Punan Bah, people who are significantly physically or mentally impaired, infertile, lame, blind, deaf-mutes, and have harelips are hampered in getting married and begetting children. Yet, Nicolaisen rationalizes restrictions of this sort with the argument that these kind of issues are dealt with as "social and moral problems, not of the individual but of the family" (p. 52). Yet, logically, without the individual's impairment, there is no problem. He then asserts that through certain adoptive practices few Punan Bah are left without children and none is denied full personhood. Yet, his article presents a bleak appraisal of the chances of people with these kinds of bodily and mental impairments ever achieving marriage, certainly a valued institution, and he never even mentions whether they do or do not enjoy an erotic sexual life. This is not to say that impaired people are never fully incorporated into the social fabric and into meaningful roles in different societies, just that up to this point in the anthropology of impairment-disability, a critical gaze has been woefully absent.

This lack of critical focus is compounded with the terminological imprecision that plagues the field. Disability often becomes the default term even when bodily/behavioral difference or impairment or another ethnophysiological or ethropsychological term would be more precise. Even when citing disability's Western medical and economic origins, scholars lapse into using it uncritically throughout an article. In 1999, Kasnitz and Shuttleworth offered what they called a pragmatic working understanding of disability-related terminology. The key is to consider the anthropology of impairment within any model of disability (see Hughes & Paterson, 1997, 1999, on the sociology of impairment). The following conceptual schema builds on this previous attempt.

Adapting from Douglas (1966), anomaly is a bodily and/or behavioral difference that falls in between cultural categories and is potentially threatening to social order. Cultures imbue anomalies with meanings and structure responses to its occurrence. Sociocultural groups may see persons whom they perceive to exhibit these anomalous differences as transgressing cultural values and threatening cultural cohesiveness, as in Douglas's model. In this case anomaly is socially construed as an impairment. Or, the group may resolve the perceived anomaly and imbue the bearer with a socially integrated role or status that is not negatively valued and does not constitute impairment. Sociocultural group members apply various indices to anomaly to determine its meaning and whether it constitutes impairment. For example, the American view of impairment is oriented toward indices of perceived functional limitations. Elsewhere, other salient ethnophysiological or ethropsychological indices, such as balance between hot/cold, wet/dry, play a key role in identifying an anomaly as a sociocultural impairment (see, e.g., Burck, 1999). In this schema a particular society with its cultural meaning system defines and situates any functional limitation or other physical/psychological statuses (see also Marshall, 1996) as impairments, just as it also constructs health and illness.

There are at least three possible responses to impairment. The person so affected may be socially integrated into a society because of prevailing cosmology and other value-orientations that center on group cohesion. A society may respond by disabling/excluding to varying degrees the persons so affected thereby constructing disability. Or, a society may reserve a transpersonal or sacred role for the persons so affected. Obviously, this schema is for analytical purposes only and that in actuality a society may combine the above kinds of perceptions/meanings/responses to certain anomalous bodily and behavioral differences depending on the contexts of everyday life.

The above view attempts to disengage as much as possible the terms impairment and disability from their original biomedical meanings with the intent of transforming them into heuristic notions for sociocultural research on oppression against people with bodily and behavioral differences. Impairment in this understanding is thus a negative sociocultural meaning stemming from the perception-constitution of a particular physical and behavioral anomaly in terms of physical/psychological function or other ethnophysiological or ethropsychological status

(see also Hughes & Paterson, 1997, 1999). This negative meaning may not appear in all domains of life, making impairment (like illness) a complex situational construct. When negative sanctions and exclusions, however, explicitly come into play in the form of particular social responses, this constitutes disability. From this perspective, the impairment–disablement sociocultural process is inherently negative. Whereas impairment is situated at the level of the cultural constitution of phenomena, that is, negatively following through with anomaly, disability is situated at the level of sociocultural response.

This is not the way that those conducting cross-cultural research usually define these terms. The World Health Organization (WHO) defines disabilities as “any restriction or lack resulting from an impairment of ability to perform an activity in the manner or within the range considered normal for a human being” (WHO, 1980, p. 28). However, even when disability is acknowledged as a negative process/response occurring between sociocultural contexts and individuals (which it is in the current anthropological research literature), cross-cultural researchers will lapse into the familiar medical and lay meaning that implicates only individual bodies and minds. Rosing (1999), for example, in an otherwise insightful article on bodily/behavioral difference among the Quechua-speaking people in the Kallawaya region in the Bolivian Andes shows on the one hand an understanding of the disablement process as a sociocultural oppressive response to anomaly but yet continues to use the term disability to refer an individual’s bodily/behavioral difference or impairment. She states, for example:

In the Andes disability can lead to two attributions (disability and vocation). In Western culture there is only one. In other words, in the Andes there is a culturally positive legitimization of disability—doubtlessly a great social resource for those affected. This is missing in Western culture. (Rosing, 1999, p. 40)

Yet, this kind of dual usage simply obscures what is actually occurring and renders any analytical distinctions between terms of no consequence.

In the anthropology of impairment–disability a radical relativism and the terminological messiness that characterizes the field has tended to stand in the way of the development of critical approaches focusing on relations of power as reproduced in an actor’s everyday practices that have taken root in anthropology as a whole (see, e.g., Dirks, Eley, & Ortner, 1994; Ortner, 1984). Yet, critical perspectives are essential in studying

impairment and disability across cultures where multiple forms of integration and exclusion often exist side by side). However, some recent work in the anthropology of impairment–disability is finally beginning to take a critical view of certain social responses to anomalous bodies or behaviors (see, e.g., Hubert, 2000a, 2000b; Hyland, 2000; Kasnitz & Shuttleworth, 1999, 2001a, 2001b, n.d.; Raji & Hollins, 2000; Sentumbwe, 1995; Shuttleworth, 2000b; Turmusani, 1998, 1999a, 1999b).

Mapping the Relations of Meaning Between Illness and Disability

Within medical anthropology the study of impairment–disability is peripheral to the core concerns of the subdiscipline (Kasnitz & Shuttleworth, 1999; Shuttleworth, 2000b). Unless there is a strong connection to a phenomenology of illness, therapeutic treatment, and/or a culture’s ethnomedical system, many medical anthropologists choose not to study disability/difference. While some medical anthropologists have expanded their focus beyond ethnomedical and therapeutic systems per se to models of social suffering and affliction (see, e.g., Kleinman, Das, & Lock, 1997), the study of impairment–disability can yet still sit uneasily within these kinds of frameworks. The fact that impairment–disability is so variously constructed cross-culturally in relation to sickness, illness, pain, and suffering often requires an initial exploratory phase of research before knowing exactly what one will be studying. One cannot simply say, “I am going to X society to study their illness meanings and patterns of therapy seeking!” or “I am going to X society to study their experience of impairment and disability!” An emically driven study must first discover which physical/behavioral differences are considered significant for a particular society.

A requisite for future ethnographic research on impairment–disability is a mapping of local meanings of anomalous physical/behavioral differences in relation to etic distinctions between illness meanings, therapeutic treatments, and pain associations across a societies’ contexts. Different societies’ models of bodily and behavioral difference would variously range across a continuum of meanings and complexes involving impairment–disability that at one end are almost completely mapped onto illness meanings and at the other end almost exclusively involve meanings of sociocultural stigma, adversity, and contention. Discerning where particular kinds of

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physical/behavioral differences fall on this continuum in terms of local meanings in different societies and the multiple contexts within these societies should constitute a major task of the disability ethnographer.

For example, Helander (1995) states, that "the Hubeer do not discriminate firmly between disability and disease. The practices and ideas surrounding disabled people can be described within the framework of health seeking and health management through which all health problems are processed." This is probably the case in many non-Western societies. Devlieger (1995), for instance, also notes that among the Songyem, disability is initially perceived and responded to as illness. However, Helander also shows how Hubeer health-seeking behavior for what we would perceive as a functional-limitation-defined impairment eventually falls off when funds run out and the gamut of therapies is exhausted. At this point, family members give up the cure and the affected individual is increasingly left to him or herself. These kinds of trajectories need to be presented in much more detail to provide us with the above kind of mapping, which would thus provide a strong basis for cross-cultural comparison. Yet, a further question is also relevant: Can this partial withdrawing of support, albeit framed within a health-seeking model, in the critical conceptual model briefly sketched above, be considered disabling?

CONCLUSION

The anthropological study of impairment-disability is becoming more cross-cultural and is beginning to develop innovative theoretical perspectives. However, the mapping of local meanings of anomalous physical/behavioral differences in relation to etic distinctions between illness meanings, therapeutic treatments, and pain associations, across different societies' totality of contexts, is virtually non-existent. Additionally, the anthropological study of impairment-disability has not much benefited from the critical work of the last 20 years within anthropology and medical anthropology. In reference to the latter, there has not been much engagement with the critical approaches of medical anthropologists such as Hans Baer, Nancy Scheper-Hughes, Margaret Lock, and Paul Farmer (however, see Kasnitz & Shuttlesworth, 1999, 2001a; Peace, 1997, 2001). While it is never wise to assume asymmetrical power relations and

oppression, in the cross-cultural study of impairment-disability, a resistance to ever conceptualizing in these terms prevails.

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