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ANTHROPOLOGICAL PERSPECTIVE OF DISABILITY

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ARTICLE INFOABSTRACT

Disability is a complex, scalar, multi-dimensional phenomenon. The social exclusion and devaluation of disabled people is widespread and persistent, both in India and worldwide. Developing more adequate understandings of the disability phenomenon and improving the participation and quality of life of disabled people are linked and urgent concerns. Prevailing approaches to disability have been flawed because they tend to individualize disability, and to neglect the social and environmental contexts which create additional burdens for disabled people, or alternatively facilitate their participation. These problems are characteristic of both mainstream medical ethics seeing impairment as a problem to be avoided and medical sociology dominated by the chronic illness approach. It is now a worldwide discipline, with particular strengths in Britain, USA, Canada and the Nordic countries, but also notable contributions from Australia, France and Germany.

INTRODUCTION

The idea of disability as a stigma has come under critical scrutiny by disability scholars and activists alike, especially by those in the Anglo-American traditions who developed "the social model of disability" Shakespeare 1998. This paradigm insists that disability is not simply lodged in the body, but created by the social and material conditions that "dis-able" the full participation of a variety of minds and bodies. Disability is thus recognized as the result of negative interactions between a person with impairment and his or her social environment. For example, ramps dramatically change the inclusion of wheelchair users in public life, an aspect of universal design that is fundamental to a fully democratic built environment Russell 2002, Crews andZavotka 2006; cf. Friednerand Osborne 2013. The social model involves a foundational critique of medicalization and its hegemony in defining and categorizing non-normative subjects. Nonetheless, the relation between embodied limitations and social discrimination remains complex and enduring KasnitzandShuttleworth 2001. Hence, we choose to use "disability" and "impairment" somewhat interchangeably. Until recently, the study of disability by anthropologists was, with a few exceptions, intellectually segregated, and often considered the province of those in medical and applied anthropology Armstrong and Fitzgerald 1996; Kasnitz 2008; Rapp and Ginsburg 2011b, 2012.

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Additionally, ShuttleworthandKasnitz point out in their 2004 review essay, "Despite this increased attention to the topic and theory of disability in anthropology, the anthropology of impairment-disability still suffers from terminological confusion, theoretical oversimplification, and a radical relativist bias that is adverse to critical approaches" ShuttleworthandKasnitz 2004, p. 153.

In addressing literature of the past decade, we show in this review article the growing incorporation of disability in the discipline on its own terms. Notably, the turn to the corporeal at the end of the twentieth century has had a salutary effect Csordas 2002, bringing in the social, experiential, narrative, and phenomenological dimensions of living with particular impairments Frank 2000. Furthermore, in the past decade, anthropologists interested in activism have found the study of disability in multiple locations to be an exciting arena of fundamental social change Holzer et al. 2001, Addlakha et al. 2009. They join disability scholars across disciplines who have worked to expand the theoretical frameworks beyond the social model, without abandoning the connection to activist concerns Groce 1999, Shakespeare 2005, BlumeandHiddinga 2010

Literature review

Our review brings together reflexive and ethnographic accounts drawn from the analytic space where anthropological and disability studies have started to converge. Many anthropologists working on disability related topics have been motivated not only by these new perspectives, but also by their

own encounters with disabling conditions—whether through their own bodies or those of kith and kin—an existential position that brings a sense of urgency to much of this work Rapp and Ginsburg 2001. Increasingly, researchers are focusing on social, political, and narrative strategies that address the experience of disability within the production, reproduction, and transformation of broader forms of social inequality. Our goal is to map recent writing on the experience of disability in relation to kinship, community, and religion, as well as the commercial, scientific, medical, and media worlds that everywhere shapes both intimate domains and public spheres. We stress the contribution of our discipline's distinctive ability to study lived experience via ethnographic methods and to imagine a broad future for critical anthropological studies of disability.

Unlike the categories of race and gender from which one can only enter or exit very rarely and with enormous and conscious effort—"passing" or "trans-gendering," for example—disability has a distinctive quality: It is a category anyone might enter through aging or in a heartbeat, challenging lifelong presumptions of stable identities and normativity. Of course, some will be more vulnerable than others owing to poverty, war, disaster, and the vagaries of health and health care, but no social category is exempt from disabling experiences, however they are defined Block et al. 2001, Boyce andWeera 2001, Fjord andManderson 2009, EideandIngstad 2011, MacMakin 2011. Despite the universality of the experience of disability, the approaches taken by scholars working out of different national contexts often vary not only by cultural norms but also in terms of policy, educational practices, forms of research funding, and social movements Varenneand McDermott 1998, Holzer et al. 2001, Ville andRavaud 2007, Addlakha et al. 2009, BlumeandHiddinga 2010, Teruyama 2011, Addlakha 2013.

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 dis- ability 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 andHerve, 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 andHerve, 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 andHerve, 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.

Conceptual models of Disability

According to the 58th round of the NSS, there were 18.5 million persons with disabilities in 2002 compared with 21.9 million reported by the Census of 2001. This translates to a 20 per cent difference in the prevalence estimates, which can be considered as significant. In this context, it is important to understand the sources of differences in prevalence estimates from the Census of India of 2001 and the 58th round of the NSS of 2002. We first present as background different ways to define and measure disability. We then review differences in the NSS and the census in disability prevalence overall and by disability type. Finally, we conclude and offer recommendations for the design of disability questions in the census and the NSS. Disability is a multifaceted and complex concept to define. Different conceptual models have been created to define disability [Altman 2001]. Over the years, the definition of disability has been evolving and can be classified into three different perspectives: i the medical model, ii the social model, and iii the ICF model.

The medical model: The medical model considers disability a problem that is directly caused by a disease, an injury or other health condition, and requires medical care in the form of treatment and rehabilitation. The medical model considers disability a health problem or abnormality that is intrinsic to an individual's body or mind. Any individual with impairment is considered disabled, whether or not the person experiences limitations in his or her life activities. Under this model, for example, individuals with any brain injury or condition such as multiple sclerosis are considered disabled.

The social model: The social model considers disability purely as a social construct and a human rights issue. Under this model, even though impairments are at the individual level, disability is the direct result of society's failure to account for the needs of persons with impairments. Disability is not the attribute of the individual; rather it is created by the social

environment and needs social change. In the social model, disability is generally understood as the result of social oppression, this oppression can start in the form of poverty and later on lead to disability.

The ICF model: The World Health Organisation WHO developed the International Classification of Impairments, Disabilities and Handicaps in the early 1980s, which was recently revised and renamed the International Classification of Functioning, Disability and Health ICF [WHO 2001]. Conceptually, ICF is presented as an integration of the medical and the social models 2001:20: "ICF attempts to achieve a synthesis, in order to provide a coherent view of different perspectives of health from a biological, individual and social perspective". The ICF model is sometimes termed the "bio-psychosocial" model of disability [Bickensack, Chatterji, Badley and Ustun 1999]. This model starts with a health condition that gives rise to impairments, and then activity limitations and participation restrictions. Impairments are problems in body function or structure as a significant deviation or loss. An activity is the execution of a task or action by an individual, while participation is the lived experience of people in the actual context in which they live. Activity and participation domains include among others, learning and applying knowledge, mobility, self-care, education, remunerative employment, economic self-sufficiency. Functioning and disability are two umbrella terms, one being the mirror image of the other. Functioning covers body functions and structures, activities and participation, while disability includes impairments, activity limitations and participation restrictions.

Emergence of Disability Studiesin Anthropology

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. R. Reid-Cunningham 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 ''phenomenological 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. Eticresearch 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. Emicresearch 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, and 1999. Louise Duvall, a medical anthropologist, began the Disability and 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 Anthropological Theories of Disability 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.

Contributions from Medical Anthropology

Medical anthropology is among the main contributors to the understanding of disability and impairment. Because medical anthropologists were some A. R. Reid-Cunningham 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; ShuttleworthandKasnitz, 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 ShuttleworthandKasnitz, 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 ShuttleworthandKasnitz, 2004.

Disability as Culture

The commonly used estimates suggest that 10 per cent of the world's population has some form of disability. There is, however, no wide agreement on the definition of disability, and few internationally comparable data on the prevalence and possible trends in the incidence of disability exist. Disability as a general topic of research, disability studies, has been dominated, particularly in the UK by sociology. Disability studies have had a close link to political activism, and disability as a social phenomenon has been understood in terms of oppression and discrimination.

Furthermore, one of the functions of empirical research has been to clarify the actual circumstances of oppression. Respecting the position of those who reject the notion of a new Disability Studies, I turn now to Goffman's work. Within more traditional sociological examinations of disability, Goffman's work is cited, used, critiqued, revisited and revised extensively. Jones et al., 1984; Geyla, 1988; Herman and Miall, 1990; Manning, 1992; Susman, 1994; West, 1996; Norwich, 1997; Nijhof, 1998 Following a brief explication of his conceptualization of disability, I will analyze a text that is typical of the kind of sociological research that has flowed from Goffman's insights. I am concerned here with drawing out the concrete ways that disability has been conceived, worked on, and represented within sociological research. Goffman's Stigma 1963:4 makes disability a sociological topic in that he speaks of societal reactions to "abominations of the body." He speaks of stigma as a "special kind of relationship between attribute and stereotype." Ibid.

"Stigma" is a social phenomenon for Goffman in that the meaning of a mark of difference attribute is generated between people. The mark becomes a stigma through interaction, thus marks of difference are not treated by Goffman as so facto leading to stigma. Depending on context and its interactants a mark of difference is regarded by others as a stigma which can eventually lead to the social construction of stigmatized people. A stigmatized person is a blemished, not quite human person. "By definition, of course, we believe the person with a stigma is not quite human." Ibid.5 A stigma is used by others to define a blemished person as different from other humans, thus making them not quite human. Stigma itself comes in three basic types or forms: 1. abominations of the body or "various physical deformities," 2. blemishes of character or "weak will, domineering or unnatural" beliefs, values and attitudes, and 3. tribal stigma or "race, nation and religion." Ibid.4 Thus many different aspects of human practices and appearances fit under the umbrella concept of stigma. This means that many different humans are regarded by others as not quite human. For example, stigma can be attached to visible and non-visible disabilities, physical abnormalities, unusual body shape or marks, interactional quirks, mental illness, and depending on the context, aspects of gender, sexuality, race, and class notice those who are endowed with an undesired difference.

In Goffman's delineation of the social construction of stigma, "normalcy" is the standpoint which does not obtrude but, rather, allows for the recognition of who or what is stigmatized. Normalcy is the unmarked site from which people view the stigma of disability. Goffman anticipates that both reader and researcher are "normals." Normals are a "we" that includes Goffman, his imagined readers, and all others who do not depart negatively from normalcy. Normals do not depart from their sense of being connected to normalcy. They do not depart, according to Goffman, because they do not possess the condition of bearing a mark of difference. The normals do not possess a stigmatized or stigmatizing attribute which will obtrude upon others and force them into an interactional relation with an undesired differentness. In so far as Goffman conceives of some human attributes as conditions of differentness and conceives of the stereotypes which surround such attributes as social phenomena produced through interaction, he can regard encounters between normals and stigmatized as "... one of the primal scenes of sociology."

Goffman, 1967:13 "Primal scene" is a term that Goffman has borrowed from Freud 1978 [1917] which refers to formative traumatic encounters, such as a child witnessing his/her parents having sex. When we encounter such traumas, according to Freud, we come to recognize our difference from others I am not my father and we make something of that difference I am inadequate, I lack. Such scenes give us an initial or primal sense of self. Just as Freud aimed to return his patients to such primal scenes in order to unwrap the mystery of their psychological problems, Goffman suggests that sociologists need to return to the primal scene of interactions between the normals and the stigmatized in order to unwrap the mystery of the genesis of social identity and difference. Interactions with disabled others are, for Goffinan, one such primal scene. Through his theory of the processes of stigmatization, Goffman unwraps the disturbing character of disabled persons whom are found in the midst of the normals. At the same time, interactions with people whose bodies are an abomination to the normals' sense of the normal body, serve Goffman as a way to highlight the concrete interactional processes of stigmatization.

Thus, in both theory and content, Goffman studies disability. "Abominations of the body" are, after all, one of Goffman's key types of stigma, and a major source of data throughout his work. It is easy to understand that disability certainly can be conceived of as an interaction between attribute and stereotype, resulting in a discredited, discreditable, failed, or not quite human person. Disability can be regarded as a powerful and obtrusive trait, a master status, marking all of the other attributes a person possesses. All of this helps to explicate the problem of disability. Goffman's research consequently represents disability both as a "thing," a problematic attribute, and also as an "occasion." Disabled people occasion a trauma of recognition which obtrudes upon a normal's sense of normalcy as an expected feature of daily life. Thus, disability is highlighted in Goffman's work as an occasion that has led to a consolidation of the "we the normals" experience, as well as to the possibility of unpacking the normal/disabled interactional scene. Disability as an occasion to unpack the meaning of normalcy is explicitly articulated by Goffman in his final two chapters of Stigma. He provides for, and thus prefigures, the necessity of unpacking norms of identity and he posits the general impossibility of normalcy's achievement even if one is "... a young, married, white, urban, northern heterosexual Protestant father of college education, fully employed, of good complexion, weight and height, and a recent record in sports." Goffman, 1963:128.

Conclusion

As can be anticipated, there are different ways to measure disability that correspond to different conceptual definitions of disability. We have described three disability measures that have been commonly used in applied disability research: impairment, functional limitation and activity limitation measures. Impairment measures of disability focus on the presence of impairment intrinsic to the individual. For example, individuals may be queried about impairments that might include blindness, deafness, mental retardation, stammering and stuttering, complete or partial paralysis. Functional limitations refer to difficulties experienced with particular bodily functions such as seeing, walking, hearing, speaking, climbing stairs, lifting and carrying, irrespective of whether the individual has an impairment or not. The above two measures of disability, impairments and functional limitations are consistent with the medical model definition of disability.Developed countries typically use disability screens that assess activity limitations, whereas developing countries tend to use impairment screens. This makes cross country comparisons of disability prevalence nearly impossible. Activity limitation screens generally lead to higher rates of reported disability than impairment screens. Indeed, individuals are more likely to identify activity restrictions because they immediately connect with daily experience; whereas the terms used to identify impairments may not be easily understood, and their nomenclature may be unknown.

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