

DEVELOPING LOCAL CONCEPTS OF DISABILITY: CULTURAL THEORY AND RESEARCH PROSPECTS

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INTRODUCTION

The anthropology of disability involves an understanding of disability as a social and cultural phenomenon. Within such a perspective, disability is created by virtue of the presence of different human bodies and their societies. Disability is not an immutable, well-defined phenomenon but one that can be understood as a universal local process. In other words, all societies must address bodily difference in their local cultural contexts. Locally produced knowledge of bodily difference involves both discourse and practice. Local knowledge of disability has been dismissed and repressed during colonial and post-colonial times as backward and irrelevant. Colonial initiatives geared to disability have largely taken Western concepts to direct initiatives of disability. Professional and scientific discourses have maintained this trend during postcolonial times. Most recently, disability advocates in the disability rights movement, speaking both in global and local contexts, have stressed that locally produced knowledge of disability is oppressive (Charlton 1998). I contend in this article that foreign discourses of disability may be culturally alienating and ultimately of little impact. Instead, I argue that research on local knowledge of disability and its cultural critique may offer an alternative towards development that is culturally rooted. In this article, I provide an agenda for research on local concepts of disability that is situated in an alternative cultural theory of disability. I define disability as a universal interstitial social status, i.e., a status that places itself between recognized categories and statuses and that is neither marginal nor elevated. This interstitial social status is neither good nor bad but always a challenge to a pre-organized world and mutually challenging for both the disabled individual and her social and cultural environment. An interstitial social status challenges culturally normative expression and communication and demands alternatives from which

disability, as cultural and social phenomenon, is identified and developed as a discourse. First, I situate disability in a contemporary context and show the need for research that documents disability as a local category. Then, I briefly take up the cultural theory of disability as an interstitial category and provide an agenda for research into local conceptualization of disability.

LOCAL AND GLOBAL CHALLENGES TO DISABILITY DISCOURSE

The concept of disability has been informed by cultures and by the history of Western nations. The concept is not fixed but highly ambiguous because what constitutes a disability is subject to personal, social and societal recognition. It happens that in Western societies the concept of disability as one that covers a number of disparate impairments is constantly being revised and therefore subject to new layers of meaning. The relationship between a society and its disabled members is one that is constantly emerging. This means that disability is historically variable and always a very *local* concept informed by cultural discourses that inform the concept. While the concept of disability has many cultural and historical roots in the West and continues to be developed in this context, part of its history is that it has been exported and infused throughout the world where in turn it may have been adapted to local contexts. This is the process of the *globalization* of disability.

In a global context, it may be overlooked that all cultures of the world have developed conceptualizations of bodily difference. Professional disciplines have not been very successful nor very active in investigating cultural definitions of disability. Yet the articulation of both the local and the global seems to be at the very heart of the contemporary experience of disability. Global discourses of disability have not developed much cultural sensitivity to local understandings of disability. Local concepts of disability are expressed in a variety of ideas and practices that relate to persons, communities, and cosmologies. These ideas are expressed through language, artistic expressions, family and social organization and ritual, religious, spiritual, and cosmological ideas and practices. Ideas that inform practice toward people with bodily differences are also contained in concepts of human development, gender roles, and political discourse. Gaining an understanding of disability from an indigenous perspective may grow from an alignment with one or several of these expressions or ideas. Research on local concepts of disability has been extremely

limited. There are many historical reasons in the colonial and post-colonial contexts, together with the appropriation of the field of disability to selected disciplines, and the dominance and overriding nature of globalization trends regarding disability, such as new practices or ideologies. There is an imbalance and a shortage of work that addresses local articulations of disability.

A CULTURAL THEORY OF DISABILITY

Theoretically, researchers have to overcome *universalistic* and *relativistic* understandings of disability. These paradigms do not adequately address the complexity of disability in cultural and historical contexts. Instead, researchers must find ways of addressing both. I have made an attempt to do so in two recent papers in which I argue that disability is an interstitial category, that is, people with impairments are situated (and situate themselves) in between the structural categories that define cultures. This is a universalistic claim that acknowledges that people with disabilities are the same and different, essentially culturally ambiguous. This claim is very different from a stigma designation of disability, with its stress upon the negative and marginalizing effects that result from disability. It is also different from the designation of disability as liminal, although I do not completely disagree with this designation (see Murphy et al. 1988). Instead, the interstitial nature of disability adds a structural component to the notion of liminality and does not imply people with disabilities are simply culturally suspended, devoid of any power. Instead, *interstitial* is intended to express the potential and the energy that results from a phenomenon that challenges and interrogates existing categories. It defines disability as a source of innovation and creativity. It also assigns some very real power of subversion of existing categories. It is obvious that these theoretical claims are rather empty without being substantiated with cultural material. This is where *relativistic* claims come into place. The interstitial nature of disability can be documented in linguistic arenas: e.g., the classification of disability terms in the Bantu noun-class system, the designation of persons with mental disabilities in English (feeble-minded, mentally deficient, mentally subnormal, mentally handicapped, mentally retarded, etc.), social practices (e.g., marriage arrangements involving Bantu and Western women with disabilities), and in artistic, spiritual and religious arenas.

PROSPECTS FOR RESEARCH ON LOCAL CONCEPTS OF DISABILITY

How can research that strikes a balance between the local and global, indigenous and expatriate, relativistic and universalistic be developed? It appears that cultural richness and resilience is predicated on a healthy interdependence between these dimensions. Research can be instrumental in building a dynamic that no longer favors a pre-modern or a modern alternative but takes advantage of what was gained from both. In the area of disability, however, the medicalization, professionalization, and globalization of disability have generally ignored and oppressed local development and indigenous thought on disability on the basis that it could not meet the needs of disabled people nor of a colonial or independent nation state. In the process, the positive and constructive elements that local development and indigenous concepts contribute and continue to provide have been lost to policy and service providers. A cultural discussion is therefore needed to recover what has been ignored and to distinguish the positive from the negative. Such an exercise would build cultural resistance and create a sound basis for interacting on a global dimension. In the remainder of this article, I would like to outline a rough plan of research to which social science and humanities oriented research can contribute.

Language

Language provides one of the most powerful tools for building a cultural understanding and critique of disability in the local context. Language informed research includes the historical and cultural analysis of concepts, proverbs, tales, narratives, and myths. They are the linguistic sediment of a culture's take on disability, they lead to an understanding of the meaning of disability itself, the use of disability as metaphor, the representations of disabled people and are an important aspect of the history of disabled people. Language is indicative of classification systems and directly leads to questions of social stigmatization and opportunities for social development. This increases understanding but also informs policy and practice that comes from the inside of cultures.

Art

Beauty and perfection are qualities that are expressed in all societies through art. The relationship between disability, beauty, and perfection is one that deserves attention because it impacts on the representation of disabled people. Indigenous ideas of disability may be influenced by cultural conceptions of bodily perfection and beauty and highly informa-

tive for understanding the consequences of living with disability in a given cultural context. Another aspect is the relation between disabled people and the production of art. How does art confront disabled people with their social status and the very private experience of disability. Does art play a conservative role or a transforming one?

Ritual, Religious, Spiritual, and Cosmological Ideas and Practices

Ritual transitions, religious sanctions and boundaries, taboos, sorcery, cosmogonies can reveal some of the deep meanings of disability that have developed as part of a cultural history. These ideas and practices are among the most powerful and resilient. They portray disability in the context of community in the largest sense of the word, including people, spiritual world, and all living beings. In addition, disabled people's access or lack of access to these ideas and practices define the cultural poverty or richness of their lives and the potential for transformation. Research in this area has been remarkably absent partly because of the Western cultural traditions in which disciplines that are concerned with disability have emerged. These disciplines have favored scientific models as the norm for knowledge production. However, the current research climate in the West, including the empowerment of disabled people, the emergence of their voice, and the response of interdisciplinary developments at the academy are promising developments.

Cultural Concepts of Human Development

Since disability is a phenomenon that manifests itself at different points of the life cycle such as fertility, birth, life transitions, old age, these ideas indicate a variety of tolerance toward human differences, the definitions of difference at various times of the life cycle. Considering the cultural meanings and role expectations at these different stages in life can add to our understanding that disability is not a monolith but variable within cultures.

Gender

The intersection between disability and gender is an important area of research. Cultural expectations of marriage arrangements, child bearing, family, occupation, employment, and career are very specifically structured in societies that additionally aim specific constraints and opportunities at disabled people along gender lines. The perspective of gender is methodologically important to show local variation of disability conceptualization within societies.

Political Discourses

Local medical and legal cultures contribute to the definition of the status of disabled people in society. These cultures operate as a result of political discourses that structure indigenous government, such as political offices, law, etc. responsible for the rules in societies that affect individuals with disabilities. In societies of the South, pre-modern political discourses, both gerontocratic and state oriented systems, have defined the very existence of disabled people. Colonial governments have been responsible for developing new structures and services that redefined disabled people. In the post-colonial and post-modern contexts, political discourses again define the local experience of disabled people.

Tools for Development

Research into local concepts of disability is to happen within disciplines, forums, and research avenues that promote the work that needs to be done. The development of an international association resulting from the conference (see Introduction) was identified as a primary goal to be pursued. Future communication mechanisms, such as a newsletter and a research journal, seem to be next on the list of priorities.

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