Generating a cultural model of disability

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Abstract

I will take this opportunity to reflect upon various existing models of disability, taking a historical and cross-cultural perspective, and considering that contemporary societies are being driven by information. In this I argue that although these models were presented as having succeeded each other, it would be more correct to consider that they co-exist and or become dominant in particular places. This matter comes more prominently to the front in multi-cultural societies. I will take on this juxtaposition of existing modes of thought on disability; this reflection will amount into a first argument for developing a cultural model of disability as one that recognizes the existence of multiple rather than one (dominant) model.

In the second part of the presentation, I will explore the possibilities of the cultural model. First, I will look into the accomplishments but also the downfalls of the so-called social model of disability. I argue that the political and ecological accomplishments of the social model must be expanded but also that to the social model must be added the creative components of disability that are reflected in identity, culture, and worldviews. Then, I will review the lead of the Deaf in accomplishing the creative element of disability. I also refer to existing but rather undeveloped elements of creative cultural development in Blind and Visually Impaired People and in Physically Disabled People.
I conclude by considering “a disability dialectic”, this is a historic process of cultural development in the course of which one can find one’s own voice.

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Introduction

We live in a globalized world. This is a world in which old categories between Us-Them as they could be established in colonial frameworks are blurred. Many of the large differences remain or even become larger, for example economic differences between North and South. But our world is also highly unique because of the vast possibilities of exchange, travel, and especially of information. All of this has important consequences of our understanding of disability.

In this presentation, I will in the first part lay the foundation of the possibility and the contours of a cultural model of disability. In the second part, I will focus on the themes and topics that are important in the development of such a cultural model.

Foundations and possibilities of the cultural model of disability

Globalization and the cultural Other

Globalization is impacting the disciplines. In the field of anthropology where I come from but in many other disciplines, this has led to important reflections on the validity of our categories of thought, the mixture between the real and the imaginary, the growing importance of the imaginary, the impact of technology on our bodies, etc. Indeed, the fact that the relationship between Us and the Other has changed, the fact that the relationship between space and place is no longer an evidence, puts challenges to the discipline(s) and indeed invites them to constantly reinvent themselves. Sometimes this is referred in anthropology as “the end of the tribe”. There are no more natives that belong to a particular place, with particular cultural customs, a particular language. Moreover the idea exists that perhaps natives were never incarcerated in particular places but that rather anthropology as a discipline invented these premises in order to be enable itself to do its work (Appadurai 1988).

On the other hand, one anthropologist, namely Robert Murphy, has identified the disabled as “the Other”. Disabled people are a reflection of their societies. In disabled people, people who identify themselves as non-disabled read who they are not. Disabled people however are not a new tribe. They live among us and the non-disabled are becoming more and more conscious of the fact that they too can and probably will be disabled for shorter or longer periods in their life times. The disabled are same *and* different (Devlieger, Rusch, & Pfeiffer 2003)

I have started this presentation with a few remarks about anthropology because it offers a good starting point on my topic today, which is basically a state of the art in our thinking of some basic categories, such as for example “Disability” or “Deafness”. Whether deafness is a disability or a linguistic minority has been at the heart of the Deaf movement (see Foster 2003, Branson and Miller, 2002).

Moreover, we can reflect on what could be the impact of globalized contexts, understood as the multi-cultural society. A concern is that members of ethnic minority groups do not participate in the disability movement or even at a much more fundamental level that persons from ethnic minority groups do not subscribe to the discourse of disability as such. Hence a more general question, “How does identification in terms of ethnic categories get blurred with identification in terms of disability?”

In our work with African Americans in Chicago we came to the conclusion that indeed ethnicity and its historical ramifications are much more important instruments to give meaning to experiences of disability (Devlieger and Albrecht, 2000). Subscription to the discourse of disability may however differ in other ethnic minorities with differing immigration histories. In this context, it may be useful to refer to John Ogbu’s distinction between voluntary and involuntary minority groups. As opposed to the situation of African Americans *in general*[1], my hypothesis would be that minority groups that have voluntarily migrated might yield power very readily to the dominant majority discourse on disability. This does however not necessarily imply a subscription to the principles of the disability movement.

In short, I would like to offer that in a context of globalization, the question arises how disability is embedded?

Theoretical resources for the cultural model on disability

Before I go into the main topic of my presentation, I would like to refer to three main theoretical resources. The first is the work of Michel Foucault whose contribution it has been to show how our basic understanding of socially important phenomena such as sickness, crime, sex and sexuality are discursively, i.e. through a language that is shared, developed in a historical process. Foucault did not write about disability but others have applied his ideas to disability (e.g., Stiker 1999). Perhaps one of the most challenging aspects of Foucault's work is that disability is discursively constructed, in other words the work of human beings, and yet in which the impact of the individual players, both those that construct and undergo the discourse, is downplayed. Applied to disability and deafness as discursive constructions, this means that the makers of the discourse are downplayed by the particular situation of the discourse, i.e. at a particular time and place, and that those that are confronted with the discourse, such as professionals, teachers, and persons with disabilities to a large extent undergo and apply the discourse.

The second theoretical resource that I would like to refer to is Jacques Derrida and his concept of "differ*a*nce". Derrida was more concerned with the process of signification and its never-ending sequence. In other words, differences create other differences. Applied to disability and deafness as cultural constructions one could say that once created they start to live a life of their own. Applied to disability and deafness, it becomes clear that indeed these are not natural categories but cultural construction. According to Branson and Miller, "the exploration of the concept of disability lays bare the contours of our society because the construction of a pathological population is at the core of the construction of every other person’s “normal” subjectivity, as they define, understand, justify, and console themselves in relation to this embodied other” (2002:x). This argument applies equally to our understanding of deafness (e.g., Baynton, 1996).

Third, I wish to briefly refer to Karl Marx’ ideas of the dialectical progression of society and the transformation of nature into culture through the application of labor. Applied to our topic at hand, it raises the question of how the relations between disabled and non-disabled people and between majority and minority groups influence the development of thinking of disability and deafness. For example, does the relation between disabled and non-disabled permit us to ask questons about the boundarries of the normative and the pathological, the limitations of our normative categories, and invite us to crossovers? Equally, does the relation between minority and majority groups with regard to disability emphasize or dilute existing categories and modes of thought?

The theoretical resources cited above make it clear that disability cannot be taken as a given but that its meanings must be understood as inherently part of culture.

Models of disability

In Figure 1, several models that conceptualize disability are juxtaposed. This juxtaposition is for analytic reasons. In real life, and in particular in the context of globalized society, this juxtaposition does not reflect evolutionary stages. Nor does this juxtaposition of models reflect the existence of these models in different places or times. Rather, in globalized contexts, one should consider the existence of modes of thought as sometimes juxtaposed, but more often intertwined. While one model may be dominant in one context, snippets of our modes of thought intervene. For example, in a hospital, disabled people, their family members, and professionals may be overwhelmed by the contours of the medical model of disability, yet equally be confronted and engage with parts of other models.

The coherency of the cultural construction of these models is based on particular model characteristics that respond to basic questions, such as “what is the source of the phenomenon?”, pointing to causal factors, “where is it localized”, indicating the possibility of multiple locations in which disability can reside, “who or what is in control”, pointing to an understanding of disability in power structures, “is it a problem?” pointing to the fact that the construction of disability as a problem is not of a necessity and indicating the possibility of historical and cultural variation. While these question point to a basic in defining disability, the next two questions point respectively to individual and/or social consequences and to the dominant approach of each mode of thought.

Let me now briefly present the different models, especially by pointing to the strength of each mode of thought and starting with the currently most dominant model, the medical model. The medical model thanks its dominance to its technical superiority and its insistence on asking questions that point to understanding the mechanics of the phenomenon of disability and its continuous feeding of the illusion that a medical solution can be found. However, throughout its existence the medical model has never proven to “resolve” disability, its solutions remaining partial, feeding into the real but sometimes also illusory promise of enhancing quality of life. The cultural coherency of the medical model is derived from its placing the source of disability in the natural world, localizing disability in the individual, pointing to human experts as being in control, operationalization as a measurable defect as perhaps its most distinctive characteristic[2],

The medical model of disability is the result of a long history in which a human-centered cosmology replaced one that placed God at the center. It benefited from an increased rationality and the development of modern societies. This view on the world has spread to all parts of the world. And while it was successful in diminishing the power of the so-called religious or moral model of disability, the latter survived and took on new dimensions. The question could be asked whether globalization also not paradoxically leads to a resurgence of moral/religious modes of thought on disability? Pointing insistently to an outside and ultimate source, God, supports the cultural coherency of the moral model. It is based on the never ending competition between good and evil and locates unfortunate events as the working of evil (in people, witches, or the emanation of evil, the Devil). While one would think that the moral model would point to a definition of disability as a punishment, this is not always the case. In some instances, disability as a problem is positively defined as a gift, a challenge given to special people (Landsman 1999; Ingstad 1997).

In the same way as the medical model defined itself in contradiction to the moral model, so did the social model in contradiction to the medical model. Perhaps the strength of the social model laid and lays in its possibility of reconceptualizing disability as the resultant of social relations and between people and their material conditions and environments.

The cultural model of disability differs in three major ways from previous efforts. First, it does not emphasize upon the existing juxtaposition but on the intertwinement of modes of thought depending on particular situations and circumstances. Therefore, it does seem congenial to define it in recognition of existing modes of thought. Such a tolerance however should not imply a non-critical practice but rather inclusive modes of thought that confirm the complexity of disability as both an existential, technical, and social phenomenon, in other words defined and reflected by culture! Secondly, the location of disability is situated in meaning itself, information, and communication. From the social model of disability, the lack of access, inadequacy or misrepresentation of information presents the core of understanding disability as cultural. In its approach, the cultural model is characterized by the critical ability of obtaining, dissecting, and applying of information. But perhaps even more important is that a cultural model of disability points to culturally determined behavior in which one develops and excells in an identity, community and worldview that embraces disability rather than rejecting it. The cultural model emphasizes the potential of disability as a state of being.

The cultural model benefits from the varying definitions of disability as stigmatizing, liminal, and interstitial. As a stigma, in the understanding of the concept as it was developed by Erving Goffman (1963), the identity of disabled people is shaped by efforts to pass as normal. While the disability studies scholarly community has a long standing in fighting the identification as solely stigmatizing, there have also been recognitions that passing-as-normal is a part of being disabled. In defining disability as a position that emphasizes the liminal, this is the being neither here nor there, Murphy (1987) has pointed to the fact that disability is a symbolic reflection of dominant categories in society, a mirror. Other have pointed to the way in which disabled people serve the non-disabled to define themselves as normal. (e.g., Thomson 1997). The liminal status of disabled people, as one being suspended between recognized categories, points to the challenge that disabled people hold out to their environments, both physical and social. Disabled people hold out a challenge to societies to reflect on itself. The notion of the interstitial brings out other aspects of contemporary identification, in which the person with a disability belongs to multiple worlds, creating each their own differences. Reflecting on those differences sets in motion a process that never ends. This seems to be particularly true for people who live in the globalized world.

Four avenues for further developing the cultural model of disability

There are four avenues that I would like to explore in the remainder of this presentation in which I would like to further develop an understanding of the cultural model. First, I would like to reflect more clearly on the ways in which the social model of disability can assist in the development of the cultural model. Second, I will look into impairment-based leadership. Third, I wish to consider information and communication as important tools in developing the cultural model. Last, I will look into an approach of working and experimenting with the cultural model of disability in what I would like to call ‘disability dialectics’.

Incorporating the critique of the social model of disability

In figure 1, I pointed out how the moral/religious, medical, and social model of disability reflect shifts in thinking. With Kuhn, one could speak of paradigmatic shifts. These shifts are real but also illusory. They present real breaks in the sense that real progress is being made in our thinking in progress when we consider a historical perspective. But thinking that one mode of thought has totally replaced another mode of thought is illusory. It is always a matter of dominance, of situational context, and in particular of time, i.e. of not yet having achieved a particular mode of thinking and the fact that older dominant modes of thinking never leave us. In other words, while the medical model may still be a dominant, it is at least juxtaposed with other ways of thinking. I have witnessed that in the United States, the religious model of disability is at times very dominantly present, e.g. within particular groups of people such as African-Americans, in particular situations in which knowledge is not available or insufficient. In European countries, who are challenged by the multi-cultural society, religious thinking on disability enters the scene.

The social model of disability has launched a revolution, both in theory and practice. Theoretically, a shift in locating disability as the result of an interaction between environment and person, has made possible to place the emphasis on the environment and on communication. These have created a new potential in the physical environment, in adapted technology, and in alternative modes of communication. Bringing in practice in the adaptation of the physical environment, in creating new technology, and in developing ways of communicating have usually resulted not only in improving the quality of life of disabled people but also in injecting additional dimensions into the living environment that have an impact on many people that are not disabled. In other words, the implementation of the social model created cultural growth and renewal. It is my contention that these have been insufficiently recognized and studied.

I would therefore propose to add another level of study, besides the level of the individual and that of the society and community: the cultural level, in which worldviews, cultural processes, are accounted for. A study in the context of the cultural model would therefore incorporate three levels, that of the individual in which the notions of identity, narrative, and individual voice are central, that of community and society in which the notion of discourse, as the sedimented historically-situated truth of a group of people, is central, and that of the worldview in which the worldmaking, i.e. both conceptually, practically and ethically, is worked out. The latter incorporates different types of knowledge: epistemic (rational-analytic knowledge), techne (practical knowledge) and phronesis (ethical knowledge). Figure 2 summarizes my proposal.

Impairment based leadership

The Deaf as no other group and the scholarship on the Deaf have shown that culture can emergence and sustain itself based on impairment. People with other sensorial disabilities (such as blind and visually impaired), physical disabilities, and intellectual disabilities (including people with autism and mental retardation) have too claimed that the emergence and sustenance of disability culture based on impairment is possible.

With Tom Shakespeare (2005), I would like to advocate for new and empirical studies on disability culture in particular context to examine the conditions under which disability culture can emerge. Moreover, it seems necessary to study disability culture as it relates to major categories of difference, such as gender and ethnic differences.

With my colleagues at the University of Illinois at Chicago, in particular Gary Albrecht and Miriam Hertz, I was able to study the conditions under which disability culture emerged in a group of violently disabled young African-American men. We concluded that while in the African American community in Chicago disability is of less or no importance in comparison to ethnicity, the condition under which the violently disabled young men became disabled facilitated the emergence of a disability culture. These conditions include: the development of discourse, the physical and social environment in which disability culture can emerge, and social alienation.

Communication as the central tool in a cultural model

Human rights and the social model of disability have produced what we now know as politically correct language. Add to this the increasing importance of images and the recognition that has emerged that representation is a historically and politically situated.

We have rather been slow to recognize that language (in word and image) is not only a corrective but also can be generative.

I would like to propose that the study of language, in terminology, sentence use, and discursive language take a more central role in disability studies. In addition, studies of communication campaigns on disability, disability humor, etc. should be taken on.

An experimental approach: disability dialectics

I wish to conclude with a fourth proposal that I would like to launch in the development of a cultural model of disability. This is a research practices that involves the exploration of the disabled and non-disabled divide. This can occur by inviting disabled and non-disabled people to enter into a relationship that is task-oriented and in which a disability critique can be generated. I would like to offer two examples.

In the framework of the 2003 European Year of Disabled People in which access and the collaboration between disabled and non-disabled people was placed central, we invited blind and visually impaired people and architects to work together in a task oriented relationship: to know each better in the context of the understanding of the use and design of public spaces. The exercise appeared fruitful in the way architects were forced to diminish their ocular centered approach to public spaces and rethink public spaces from other, non visual angles. The exercise was also repeated in the area of tourism where other dimensions of exploring and understanding historical places can be approached through touching and hearing.

A second example is in the area of participative action research. In a study of the access of public places in Chicago, disabled people identified places that they would like to use more often, entered into a relationship with owners of these places (e.g. shopkeepers, owners of movie theaters, etc.) and both inquired and proposed changes in the physical environment. When they followed up their visit in a six month period of time with another visit, they found that changes has taken place in about 30% of the cases.

The examples above show research in a mutually beneficial relationship, a going back and forth to find a win-win result, a positive dialectic. Thank you.

Notes

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1. There are exceptions. In a study of violently disabled young African Americans, there was much evidence that a disability culture emerged, which involved both the generation of a unique discourse and an involvement with dominant discourses of disability in American society.

2. The late identification of certain disabilities is immediately connected to the possibility of testing. This is in particular the case for cognitive (e.g. dylexia), behavioral and emotional (e.g., autism, hyperactivity syndromes, depression) disabilities. In a few remarkable studies, it has been shown that the medicalization of certain phenomena (such as child abuse) is difficult or even impossible (e.g. the attempts to define and measure ‘fugitive syndrome’).

Literature Cited

Appadurai, Arjun
1988 Putting Hierarchy in Its Place. *Cultural Anthropology* 3(1):36-49.

Branson, Jan and Don Miller
2002 *Damned for Their Difference: The Cultural Construction of Deaf People as Disabled.* Washington, DC: Gallaudet University Press.

Devlieger, Patrick & Albrecht, Gary
2000 Your Experience Is Not My Experience: The Concept and Experience of Disability on Chicago's Near West Side. *Journal of Disability Policy Studies* 11(1), 51-60.

Devlieger, Patrick; Frank Rusch & David Pfeiffer
2003 Rethinking disability as same and different! Towards a cultural model of disability. *In* Patrick Devlieger, Frank Rusch & David Pfeiffer, eds. Rethinking Disability: The Emergence of New Definitions, Concepts and Communities. Pp. 9-16. Garant: Antwerpen.

Foster, Susan
2003 Examining the Fit Between Deafness and Disability. *In* Patrick Devlieger, Frank Rusch, & David Pfeiffer, eds. Rethinking Disability: The Emergence of New Definitions, Concepts and Communities. Pp. 111-1429.

Goffman, Erving
1963 *Stigma: Notes on the management of spoiled identity*. Englewood Cliffs: Penguin.

Ingstad, Benedicte
1997 *Community-Based Rehabilitation in Botswana: The Myth of the Hidden Disabled.* Lewiston, NY: Edwin Mellen Press.

Landsman, Gail
1999 Does God Give Special Kids to Special Parents? Personhood and the Child with Disabilities as Gift and as Giver. *In* Transformative Motherhood: On Giving and Getting in a Consumer Culture. Linda L. Layne, ed. Pp. 133-165. New York: New York University Press.

Murphy, Robert F.
1987 *The Body Silent*. London: Phoenix House.

Shakespeare, Tom
2005 Review article: Disability studies today and tomorrow. *Sociology of Health and Illness, 27(1),* 138-148.

Thomson, Rosemarie Garland
1997 *Extraordinary Bodies: Figuring Physical Disability in American Culture and Literature*. New York: Columbia University Press.